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People's experiences of living with severe health conditions

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This thesis has been submitted as part of the fulfilment of requirements
for the degree of
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List of Abbreviations

HD	Huntington's Disease
DNA	Deoxyribonucleic acid
RNA	Ribonucleic acid
DMA	Directed mutation analysis
UK	United Kingdom
CASP	Critical Appraisal Skills Programme
IPA	Interpretive Phenomenological Analysis
HRA	Health Research Authority
NICE	The National Institute of Clinical Excellence
PTSD	Post Traumatic Stress Disorder
PTSS	Post Traumatic stress symptoms

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Declaration

This thesis is an original piece of my own work, that has been submitted for the Clinical Psychology Doctorate at the Universities of Coventry and Warwick. The work detailed with this project has not been submitted for any other qualification or to any other institution. Emergent findings from the empirical paper will be presented as a poster presentation at the University of Warwick Postgraduate Research conference. The thesis was undertaken with the academic and clinical supervision of Dr Carolyn Gordon, Ms Jackie Knibbs (Coventry University) and Dr Terry Hatton (Queen Elizabeth Hospital). Except for the collaborations stated, all material presented within this thesis documents my own work. The literature review was written in preparation for the Journal of Genetic Counseling, while the empirical paper was written for submission to the British Journal of Health Psychology.

Summary

Treating people living with severe health conditions has, and always will be, a fundamental part of the National Health Service. Given the complex nature of conditions such as Huntington's Disease and Cancer, research exploring the impact severe health conditions can have on those affected is of paramount importance.

Chapter one is a systematic review utilising a meta-ethnographic approach to explore qualitative research portraying people's experiences of genetic testing for Huntington's Disease (HD). Electronic databases cataloguing relevant research were searched which, combined with manual searches, resulted in eleven studies suitable for inclusion. Three meta-themes were identified, highlighting the complex and individual nature of undergoing genetic testing, together with the potential emotional and behavioural consequences. The implications of such findings, together with clinical recommendations are considered.

There is a dearth of research exploring what it is like to live with cancer as a young person in the United Kingdom. Chapter two is a qualitative research study that explored the lived experiences of young people (13-24 years) who had recently been diagnosed with cancer. Utilising an interpretative phenomenological approach, emergent findings related to the adversarial nature of being diagnosed with cancer, with young people speaking to the unjust nature of battling this disease at such a youthful age, questioning their identity and having to navigate a new, and at times, uncertain world. The clinical and service implications of these findings are discussed, alongside areas of future research.

Chapter three represents the author's reflective account of conducting this research. From exploring initial motivations, to evaluating the role of "insider" and "outsider" perspectives, the author explores the reciprocal nature of conducting qualitative research, particularly in relation to the mutuality felt between himself and his participants.

Overall word count: 19,116

Chapter One
Systematic review paper

**People's experiences of predictive genetic testing for Huntington's
disease: A systematic review of the qualitative research**

This chapter was prepared for submission to the Journal of Genetic Counseling, Appendix A provides detailed author guidelines from this journal. The word count for this chapter, excluding abstract, figures, tables and references, is 7,964

1.0 Abstract

Purpose: Huntington's disease (HD) is a neurodegenerative genetic condition with no current cure. While the psychological impact of testing has been explored in previous research, quantitative studies have yielded mixed results. The aim of this systematic review was to produce a synthesis of the qualitative evidence base examining individuals' experiences of predictive genetic testing for HD.

Study Design: A meta-ethnographic synthesis was conducted. A total of five electronic databases cataloguing relevant research (e.g. psychology, nursing and medicine) were searched, resulting in a total of 11 studies for analysis.

Major findings: Three meta-themes were identified: 'discovering the truth', 'facing the truth' and 'sharing the truth'. People's experiences of testing varied, with some associating the experience with affirmative life decisions, whilst others spoke about the distress and difficulty that followed the result. Various factors that contributed to these experiences were explored.

Main conclusions: Whilst there were commonalities across the study's findings, there were also divergences, highlighting the complex and individual nature of genetic testing for HD. With potential significant emotional and behavioural consequences, clinical and research implications are considered.

Key Words: *Huntington's Disease, HD, Genetic Testing, Gene Positive, Experiences, Meta-ethnographic*

Abstract word count: 188

1.1 Introduction

1.1.1 Genetic Testing

Genetic testing is a process defined as “the analysis of human DNA¹, RNA², chromosomes, proteins, and certain metabolites in order to detect heritable disease-related genotypes, mutations, phenotypes, or karyotypes for clinical purposes” (Burke, 2002, p. 1867). Scientific advances have seen substantial progress in the understanding of human genetics. Whilst knowledge of the human genome sequence has grown for many diseases, advances have arguably created more lines of enquiry. Furthermore, transforming findings into clinical intervention is not straightforward (Miller, 2004)

It is proposed that in the future, information about our genes will lead to the routine use of diagnostic testing, based on genetic markers for common diseases such as asthma, coronary artery disease, and diabetes (Miller, 2010). There is also the potential for genetic information to influence treatment of human diseases. Such prospects include ‘gene therapy’ for diseases such as cancer, where the potential to replace ‘faulty’ or ‘missing genes’ may become a reality. With the number of available genetic tests expanding, research exploring how such tests are applied, is of great importance (Amos & Patnaik, 2002).

Currently, there are three main categories of genetic testing which examine changes or mutations: diagnostic, carrier screening and predictive (Miller, 2010).

¹ Deoxyribonucleic acid

² Ribonucleic acid

Diagnostic testing is used to validate a diagnosis in people already displaying clinical symptoms, whilst carrier screening tests a person free from disease (a carrier) who could potentially pass on this change to their offspring. Finally, predictive genetic tests can identify the presence of mutation that can cause a disease in people who are currently asymptomatic (Burke, 2002).

There are a variety of benefits to predictive genetic testing. For example, tests are now available to identify genes that increase the likelihood of a variety of cancers. This has helped people become more aware of potential symptoms and spot early signs of the disease, aiding early detection and treatment (Miller, 2010). However, uptake of genetic testing outside of cancer related conditions is limited (Forrest, Delatycki, Skene & Aitken, 2011). Since predictive testing does not always lead to treatment, its use for potentially fatal diseases with limited or no treatment options, has been shown to lead to psychological distress and needs to be considered carefully (Oster et al., 2008).

1.1.2 Huntington's Disease

Huntington's disease (HD) is an autosomal dominant neurodegenerative condition characterised by involuntary movements, psychiatric manifestations and cognitive decline (Sturrock & Leavitt, 2010; NHS.uk, 2018). It has a reported worldwide prevalence rate of between 4 and 12 people per 100,000 and a disease trajectory of 10-20 years before death (Myers, 2004; Pringsheim et al., 2012; NHS.uk, 2018). The average age of onset is between 40 and 45 years and there is currently no cure, with treatment focusing on symptom management and quality of life (Sturrock & Leavitt, 2010).

Directed mutation analysis (DMA) developed in 1993, means people at risk of developing HD can discover their carrier status with 100% accuracy (Evers-Kiebooms & Decruyenaere, 1993). Given the definitive and potentially life changing implications of predictive genetic testing, research examining the psychological implications is crucial (Leventhal, Leventhal & Contrada, 1998; Leventhal, Leventhal & Cameron, 2001; Rolland & Williams, 2005)

1.1.2.1 Genetic testing for Huntington's Disease

Uptake in predictive genetic testing, by asymptomatic family members at risk of developing HD, has been consistently low (Sobel & Cowan, 2000). Recently, Baig et al. (2016) conducted the largest UK study on predictive genetic testing for HD, examining 22 years of anonymised data. Findings revealed that the majority of people at risk of HD (>80%) had not undergone predictive testing. With future trials and therapies for HD likely targeting presymptomatic individuals, research looking at factors impacting on test uptake is of significant public health value (Baig et al., 2016).

1.1.2.2 Psychological Impact of predictive genetic testing for Huntington's Disease

Researchers and clinicians have attempted to apply several psychological models to understand people's reactions to predictive genetic testing and HD. One of the most notable in relation to its application and evidence base, is the Common-Sense Model of self-regulation of health and illness developed by Leventhal et al. (1998).

Employing this model to help explain potential reactions to a diagnosis of HD suggests that given its uncontrollable and fatal consequences, the possibility of such

a diagnosis would be appraised as highly threatening and extremely distressing. Despite this, evidence relating to psychological impact is equivocal, with studies employing various methodologies leading to different findings (Duncan et al., 2008).

1.1.3 Quantitative research

Decruyenaere et al. (1996) assessed the impact of predictive genetic testing for 53 participants using pre- and post-test psychometric measurements and self-report data. Findings revealed no significant change in anxiety and depression in the case of a positive test result. Furthermore, researchers found the mean personality profile including ego strength, remained unchanged one year after the test. Timman, Kievit and Tibben (2004) measured psychological stress responses amongst 49 participants (20 carriers and 29 non-carriers). Results highlighted no significant differences amongst the two groups, with only slight changes from baseline observed three years post testing. Furthermore, hopelessness scales only highlighted a difference in carriers one week after disclosure, with scores returning to similar levels after six months.

Crozier, Robertson, and Dale (2015) systematically reviewed 8 studies using standardised measures to examine pre-symptomatic psychological distress associated with DMA genetic testing. Results suggested no significant differences in psychological impact amongst non-carriers and those found to have the disease. Further analysis revealed that people who were symptomatic did show increased signs of psychological distress compared to non-symptomatic carriers and non-carriers, suggesting that distress may be an early manifestation of the disease rather than an implication or awareness of gene status (Lickleder, Wolff & Barth, 2008).

1.1.3.1 Methodological Limitations

Quantitative literature, together with the review by Crozier et al. (2015) has focused on papers utilising standardised measures. Despite finding certain differences in psychological impact between carriers and non-carriers, the overall outcome of quantitative research to date implies no significant adverse impact irrespective of test outcome. However, there are several methodological and conceptual limitations to this type of research.

Only one of the studies included in the review by Crozier et al. (2015) utilised a specific measure for HD (Unified Huntington's Disease Rating Scale, Witjes-Ané et al., 2002), with all other studies using standardised generic measures of psychological constructs found in the general population. Crozier et al. (2015) suggested the use of such measures may not be sensitive enough to detect emotional reactions reported by individuals experiencing this particular phenomenon. Furthermore, the review recognised these measures were employed in a pragmatic manner to assess impact, and as such were not explicitly derived from a theoretical understanding of how genetic testing might affect people's lives. Crozier et al. (2015) concluded that the lack of clinically significant findings when using psychometric instruments may represent absence of distress, however suggested further research was needed to ensure these findings were not an artefact generated by the use of unsuitable measures. Furthermore, given the low uptake in predictive genetic testing, such findings only reflect a minority of experiences, and as such more in depth qualitative enquiry examining people's experiences would be helpful.

1.1.4 Qualitative Research

Qualitative research examining people's experiences of genetic testing for HD has revealed a more diverse range of experiences than indicated by quantitative research. A study by Hagberg, Winnberg, and Bui (2011) used content analysis to explore experiences of living as a mutation carrier of HD. Common themes of distress amongst carriers were found and included feelings of fear, regret and hopelessness (Hagberg et al., 2011). Schwartz (2010) used a holistic content approach to explore people's experiences of undergoing genetic testing for HD. Data analysis revealed the presence of several distressing emotions, such as shock, fear and frustration (Schwartz, 2010). Adverse psychological consequences have also been reported, regardless of test outcome, with carriers often struggling to come to terms with a life-limiting disease, and non-carriers reporting feelings associated with survivor guilt, as well as emotional numbness and difficulties within the family (Hayden & Bombard, 2005).

1.1.5 Rationale

Despite most quantitative research examining the impact of predictive genetic testing for people at risk of HD reporting non-significant results, qualitative studies have shown common themes associated with distress and difficulty (Broadstock, Michie, & Marteau, 2000; Meiser & Dunn, 2000; Lickleder, Wolff, & Barth, 2008; Schwartz, 2010; Hagberg et al., 2011; Crozier et al., 2015). The increase in qualitative research in this field has now changed the focus of enquiry to include exploration of individual experiences of genetic testing and as such has the potential to provide a more in-depth picture.

1.1.6 Aims of current review

Previous qualitative research examining the effects of predictive genetic testing has found varying psychological consequences. Given the deteriorating and incurable nature of HD, together with the introduction of mutation analysis, a more in-depth enquiry of qualitative research exploring the impact of predictive testing, must be considered (Dudok DeWit et al., 1998). With recent quantitative reviews by Broadstock et al. (2000), Meiser and Dunn (2000) and Crozier et al. (2015) reporting no significant clinical distress amongst those undergoing predictive genetic testing for HD, a systematic review of the qualitative evidence base is required, to establish a more detailed insight into people's lived experiences.

The aim of this current review is to provide an interpretative qualitative synthesis of the empirical evidence relating to the experiences and psychological implications of predictive genetic testing for HD, in at risk individuals. A secondary aim is to explore what information qualitative studies provide in relation to uptake of predictive genetic testing. It is hoped the findings of the review will inform future research and support clinicians in informing pre-and post-counselling support.

1.2 Method

1.2.1. Search strategy

Ethical approval for this review was sought from Coventry University Ethics Committee (See Appendix B). A systematic investigation of literature examining ‘Experiences of predictive genetic testing for Huntington’s disease’ was conducted in October 2017 and updated in March 2018. Preceding the systematic search, the researcher and subject librarian examined relevant database specific thesauruses and keyword heading lists (e.g. Medical Subject Headings; MeSH) in order to identify further appropriate terms. Table 1.1 provides a list of the databases cataloguing pertinent research (i.e. those associated with psychology, medicine and nursing). Reference sections of included articles were hand-searched for additional studies. Online attempts to acquire relevant grey literature were also undertaken i.e. Google Scholar, Open Grey and Open Door. Table 1.2 outlines specific search terms, together with the approaches to Boolean and Truncation operators employed in the search. Search terms were isolated to title, abstract and key words of studies to increase probability of identifying relevant research.

Table 1.1 Databases included in the systematic investigation

Database	Host
AMED (Allied and complementary Medicine Database)	Ovid
CINAHL (Cumulative Index to Nursing and Allied Health Language)	EBSCO
PsychINFO (Psychological Information Database)	Ovid
MEDLINE (Medical Literature Analysis and Retrieval System Online)	Ovid
Scopus	Elsevier

Table 1.2 Search terms, truncation and Boolean operators

Concept	Search terms
Experience	Experience or Impact or Effect or Psychological Consequence or Consequence
Genetic Testing	Genetic or Test* or predictive or Screening or Counselling
Huntington's Disease	Huntington's Disease, Huntington's or HD
Qualitative Research	Qualitative Research/ or Experience or IPA or Grounded Theory or Thematic Analysis or Discourse Analysis or Content Analysis

1.2.2 Eligibility Criteria

Original qualitative research and mixed methods papers pertaining detailed qualitative accounts of peoples lived experiences of predictive genetic testing for HD were included. While there were no restrictions placed on the gender of participants, research that focused on people who were not at risk of developing HD or were at risk of developing other genetic conditions were excluded. No limits relating to qualitative method, sample size or recruitment strategies were implemented.

However, quantitative research or non-original articles (i.e. reviews or books) were excluded. Due to medical advances in screening and the arrival of DMA in 1993, research before this date was excluded. Research with participants under the age of 18 was excluded in line with the NHS age limit for genetic screening. Table 1.3 provides a summary of the inclusion and exclusion criteria.

Table 1.3. Inclusion and Exclusion Criteria

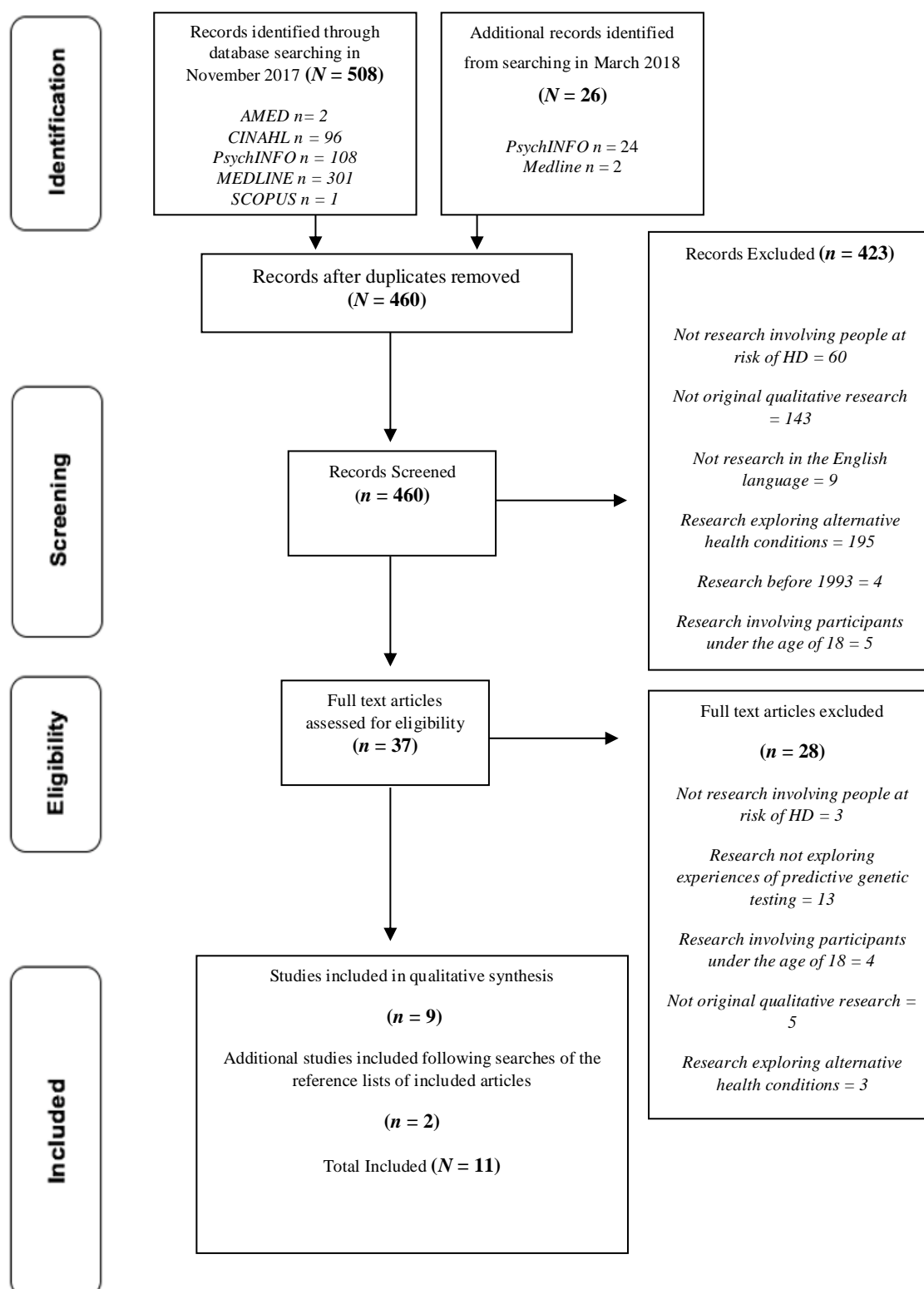
Criteria	Inclusion	Exclusion
Experiences of predictive genetic testing	Research exploring experiences of individuals undergoing predictive genetic testing	Research exploring individuals at risk of HD who are not in the process of undertaking/have not undergone, predictive genetic testing
Research Design	Qualitative Research Mixed Methods (Qualitative Aspect)	Quantitative research, non-original articles (e.g. reviews, books or editorials)
Sample	Humans	Animals
Genetic Status	At risk of developing HD	Not at risk of developing HD/other genetic conditions
Age	>18	<18
Year of publication	≥ 1993	<1993
Gender	Male and Female	N/A
Language	English	Non-English

1.2.3. Study Identification

The process of study selection was recorded using the “Preferred Reporting Items for Systematic Reviews and Meta-analyses” (PRISMA) flow diagram shown in Figure 1.1. A total of 534 original studies were identified from electronic database searches, with no additional “grey” articles being identified. Seventy-four duplications were detected and removed by computer programmes and the author following crosscheck examination. Titles and abstracts of the remaining 460 articles were inspected for inclusion. A total of 421 studies were eliminated in line with the review’s eligibility

criteria. A further two studies (PhD Thesis) were excluded because full text versions of the research were unavailable. Full texts of the remaining 37 articles were then examined for inclusion. Following full text screening, 28 articles were removed for failing to meet eligibility criteria. This resulted in a total of 9 articles for systematic review. An additional 2 studies were incorporated into the review following hand-searching reference lists of relevant articles, leading to a total of 11 papers for review.

Figure 1. 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (PRISMA) diagram (Moher, Liberati, Tetzlaff, Altman, & Group, 2009)



1.2.4. Quality Appraisal

On completion of the systematic search process, studies selected for inclusion were assessed using a quality assessment framework (Critical Appraisal Skills Programme - CASP, 2017). The CASP Qualitative Checklist was developed in partnership with Better Value Healthcare Ltd (BVHC), which was set up to promote good practice of value-based healthcare (CASP, 2017). The CASP was specifically developed for use in systematic reviews and can assist in assessing the quality of original research articles (Hannes, Lockwood, & Pearson, 2010). The CASP is one of the most ‘user-friendly’ and ‘widely used’ quality assessment tools (Verboom, Montgomery, & Bennett, 2016). However, in a comparative assessment of three popular quality assessment tools, the CASP’s sensitivity to descriptive, interpretive and theoretical validity was questioned (Hannes, Lockwood, & Pearson, 2010). In order to address these limitations, this project has utilised an augmented version of the CASP, which includes four items adapted from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (The Joanna Briggs Institute, 2014). The adapted CASP instrument (Appendix C) has been used in previous research by Verboom, Montgomery, and Bennett (2016) with good effect, and contains 12 items, all of which can be answered with either ‘Yes’, ‘No’, or ‘Unclear’.

Further adaption of the marking criteria was required to permit calculation of inter-rater reliability for individual studies. Each item was scored 1 for ‘No’, 2 for ‘Unclear’ and 3 for ‘Yes’. These adaptations were implemented to aid cross checking amongst reviewers and are not designed to yield an overall numerical ‘score’ for the methodological quality of studies. Rather, the questions listed within this framework are designed as prompts to guide reviewers in a critical analysis. As there is no

consensus on the relative weight each characteristic of a study has on overall quality, the presentation of a simple summed score would risk being more misleading than informative (Verboom, Montgomery, & Bennett, 2016).

1.2.4.1 Outcome of quality assessment

To enhance the reliability of the quality assessment, an additional researcher rated 6 out of the 11 articles independently against the same quality criteria. An inter-rater reliability analysis using the Kappa a coefficient was performed (Cohen, 1960). These ranged from 0.66-1.00 for each of the six studies, while the overall Kappa score was 0.86 ($p < .0001$), indicating good inter-rater reliability (Appendix D).

Given the wide variety of quality assessment tools available, together with the lack of coherence about assessment criteria, no studies were excluded due to methodological quality. Overall, the aim and purpose of the articles included in the review were well stated, as was their chosen methodological design. Results were generally well reported and often justified with the use of quotations. The majority of studies reported sufficient information relating to approach to data analysis and information relating to data collection was generally well specified. However, reporting of patient demographics were less consistent, as were descriptions of researchers' epistemological position and framework. Furthermore, reflexivity tended to be inadequately reported, as is common within empirical research (Walsh & Downe, 2006).

1.2.5. Study characteristics

A summary of the 11 studies included in this review is provided in Table 1.4. The

studies had a variety of aims, but all led to findings relating to people's experiences of predictive genetic testing for HD. Ten studies collected data via face-to-face interviews and one study used telephone interviews, providing a cohesive method of data collection methods throughout the sample.

There were variations in the reporting of participant demographics. Not all studies reported the age of individual participants; the age range of those that did was between 18 to 74. Given that the population within all the studies accounts for adults across the life span, concerns relating to the transferability of the findings to different age groups should be limited. All studies apart from the case studies used both male and female participants. Four of the studies were conducted in the United States, three in Sweden, two in the United Kingdom, one in Australia and one used participants from both Canada and the United States. Additional information is provided in Table 1.4.

In relation to data analysis, a range of methods were employed. Two studies used Interpretive Phenomenological Analysis, two used content analysis, whilst a further two studies used a descriptive case study approach. One study utilised grounded theory, and one used thematic analysis. One project combined grounded theory and thematic analysis, and one used narrative enquiry. One study's method of analysis was unclear, suggesting data was analysed in accordance with conventions of qualitative data analysis

Table 1.4 Summary of included studies

Author/Date	Country	Study Aim	Method of Analysis	Sample population	Method of data collection	Key Themes/Findings	Quality Assessment Score
Andersson et al, 2013	Sweden	To describe the experiences of undergoing a presymptomatic genetic test for HD	Case study	18 interviews with an “at risk” female and her partner covering a period of 15 months	Recurrent Interviews	Findings revealed several themes including, reasons for testing, waiting for the outcome, issues with disclosure, facing the future and trying to adapt	31/36 (Kappa = 0.66)
Andersson et al, 2016	Sweden	Describe a young couple’s long-term experiences and consequences of a predictive test result for Huntington’s disease	Case study	18 interviews with an “at risk” female and her partner covering a period of 2.5 years	Recurrent interviews and informal conversations	Variety of long-term consequences, characterised by anxiety, repeated suicide attempts, financial difficulties and divorce.	28/36
Chapman, 2002	United Kingdom	To retrospectively explore the views of people affected by HD and to assess the impact of a positive predictive test result	IPA	21 adults (11 male and 10 female) aged between 19-60 years	Semi-Structured Interviews	A number of key themes were identified and included the age of testing; the implications of living with the knowledge of gene status; and the potential impact on future reproductive issues.	27/36

Cox & McKellin, 1999	Canada	To explore the social meanings and lived experiences of people undergoing predictive testing for Huntington's Disease.	Thematic Analysis	22 adults (7 males and 15 females) at risk of developing HD and 41 family members.	Semi-structured Interviews	Results found a number of social, biographical and temporal factors that families consider when discussing risk and its modification through predictive genetic testing.	26/36 (Kappa = 0.86)
Gong et al, 2016	USA	Explore how the knowledge of Huntington's Disease gene-positive status influences pre-symptomatic young adults	Combination of grounded theory and thematic analysis	14 young adults (12 female and 2 male) aged between 18-35 years	Semi-Structured Interviews	Knowing one's gene-positive status result can promote positive changes in individuals approach to life. However, results were also shown to impact on career choices, romantic relationships and family planning	31/36 (Kappa = 0.68)
Hagberg et al, 2011	Sweden	To explore the long term (>5 years) experiences of being a mutation carrier for Huntington's Disease	Content Analysis	10 adults (4 male and 6 female) aged between 34-62 years	Semi-Structured Interviews	Five main themes and 14 sub-themes emerged from the interviews that reflected the lived experiences of being a mutation carrier up to a decade after receiving the test result. Positive changes included a greater appreciation of life and closer family relationships.	27/36

						On the other hand, decisional regrets and negative impacts were reported.	
Schwartz, 2010	USA	To explore the meaning of being diagnosed with Huntington's Disease	Narrative inquiry	10 adults (3 males and 7 females) aged between 20-74 years	Semi-structured interviews	Several psychological implications were found. Analysis yielded four main themes; the discovery of HD, conformation of gene status, disclosure and living with the consequences	27/36
Sobel & Cowan, 2003	USA	To examine the impact predictive genetic testing for Huntington Disease has on the family system	Grounded Theory	18 families, comprising of 55 individuals, who had been tested at least one-year prior to the study and were asymptomatic at the time (No further demographic information available)	Semi-structured interviews.	Predictive genetic testing was found to have an impact on a variety of areas including, role changes, family membership and cohesion, in addition to a number of changes in patterns of communication.	29/36 (Kappa = 0.86)
Taylor, 2004	Australia	To explore predictive test decision-making by individuals at risk for Huntington's Disease	Unclear – “in accordance with conventions of qualitative data analysis”	16 adults (7 males and 9 females) aged between 20 - 60 years	Semi-Structured Interviews	Findings suggested predictive testing was regarded as a significant life decision and had important implications for self	28/36 (Kappa = 0.87)

						and others, including family planning and preparing for the future.	
Theed et al, 2017	United Kingdom	Investigate how people who tested positive Huntington's disease understood and experienced psychological distress and their expectations of psychological therapy	IPA	9 adults (4 males and 5 females) aged between 24 and 56 years	Semi-structured Interviews	Three superordinate themes: attributing psychological distress to HD, changes in attributions of distress over time, and approaching therapy with an open mind.	30/36 (Kappa = 1.00)
Williams et al, 1999	USA	To describe the expectations of those seeking presymptomatic gene testing for Huntington disease	Content analysis	17 adults (11 female and six male) aged between 18-59 years	Semi-Structured Interviews	Common themes included anticipating relief from uncertainty, hoping to plan for the future and wanting to know if their children were at risk of developing HD. Results also spoke about of people anticipated loss of family support from relatives as well as venturing into the unknown, and planning for disclosure.	30/36

1.2.6 Synthesis of the findings

A meta-ethnographic approach was selected to integrate findings and arrive at an overall qualitative synthesis (Atkins et al., 2008; Noblit & Hare, 1988; Purc-Stephenson, & Thrasher, 2010). Meta-ethnographic approaches are appropriate for integrating and interpreting qualitative data and are regularly used within health and social care research (Atkins et al., 2008). Some authors have questioned its use for combining findings of primary research, particularly those adopting different theoretical perspectives (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). However, many argue the strength of this approach lies in its attempt to preserve interpretive properties of the original data. In relation to the current review, synthesis was guided by the model developed by Noblit and Hare (1988), listed in Appendix E.

Papers were read and re-read to become familiar with content and detail of the studies and to begin the process of obtaining 'metaphors' or emerging themes from each of the 11 studies. Data from all studies was extracted by the lead researcher. To reduce potential bias, data was also extracted from a selection of studies by an additional researcher and compared, with no significant differences being revealed.

Given the number of themes reported and different research designs, in line with other meta-ethnographies (e.g. Atkins et al., 2008; Purc-Stephenson & Thrasher, 2010); a thematic analysis was conducted on the key themes from each study. Each article was coded according to themes relating to the research question³. This was achieved by repeating rounds of analysis whereby the researcher arranged each

³ [What are the experiences and psychological implications of predictive genetic testing for HD in people at risk of developing the disease]

article in date order, comparing themes and concepts from paper 1 with those emerging from paper 2. The synthesis of these two papers were then compared and revised considering paper 3. The process was repeated until themes were revised on the basis of all 11 articles. Finally, the researcher developed meta-themes that provided an over-arching framework accounting for the findings generated from the original articles and incorporated the synthesis of themes produced by the analysis. A list of themes and meta-themes are listed in table 1.5.

1.2.7 Reflexivity

The author is male and has had exposure to Huntington's disease within his family, with his maternal grandfather being diagnosed in 2014. It is acknowledged that these experiences may have influenced his interpretation of the findings from this review, and as such the above steps (i.e. inter-rater reliability and the use of an independent researcher to compare themes) were employed to try and reduce potential bias.

1.3 Findings

Three meta-themes were identified from the synthesis of 11 articles. These were 'Facing the truth', 'Living with the truth' and 'Sharing the truth'. Within each of the meta-themes, a chain of subthemes was developed. Table 1.5 identifies which meta-themes, and subthemes, were considered within each of the articles.

Table 1.5 Meta-themes and Sub-themes ascertained in the systematic review

Meta-themes	Facing the truth		Living with the truth		Sharing the truth	
<i>Sub-Themes</i>	<i>Uncovering Reality</i>	<i>Striving for the truth -fact as a foundation?</i>	<i>Adjusting to loss</i>	<i>Re-establishing of self</i>	<i>Do they need to know?</i>	<i>Can they handle knowing?</i>
Theed et al, 2017		✓	✓			
Andersson et al, 2016		✓	✓	✓	✓	
Gong et al, 2016		✓	✓	✓		
Andersson et al, 2013	✓	✓	✓	✓	✓	✓
Hagberg et al, 2011		✓	✓	✓	✓	✓
Schwartz, 2010	✓	✓	✓	✓	✓	✓
Taylor, 2004	✓	✓		✓	✓	✓
Sobel & Cowan, 2003			✓	✓		
Chapman, 2002	✓	✓	✓	✓		
Cox & McKellin, 1999	✓	✓				✓
Williams et al, 1999		✓	✓	✓	✓	✓

1.3.1. Facing the Truth

This meta-theme represents information about how people come to acknowledge the presence of HD within their families, together with the implications this had on their decision to be tested. There were two subthemes: ‘Uncovering Reality’ and ‘Striving for the truth: Fact as a foundation?’

1.3.1.1 Uncovering Reality

This subtheme arose from participants’ accounts of how they first discovered HD, together with their initial thoughts and reactions. Five articles discussed participants’ experiences of finding out about HD (Andersson et al., 2013; Schwartz, 2010; Taylor, 2004; Chapman, 2002; Cox & McKellin, 1999). Schwartz (2010) reported how the discovery of HD often surfaced when participants became aware that something was ‘awry’ with a relative. For most, HD was a ‘new entity’, bringing about an array of emotions, including ‘shock’, ‘surprise’, ‘frustration’, ‘isolation’, and ‘relief’ (Schwartz, 2010 p.159). Furthermore, several of the participants’ stories alluded to the private nature of the disease.

“It was a secret until I was an adult and my mother’s symptoms had already progressed”

(Schwartz, 2010, p. ⁴159)

Reasons behind this enigmatic behaviour seem to be multifaceted, with Schwartz (2010) suggesting a range of potential explanations including: new mutations, paternity issues, early death of parents, late onset, or infrequent contact with extended family. Despite being a well reported study, with several participant

⁴ p refers to page number/s from which quotes were obtained

quotations, the small amount of information in relation to data analysis and the absence of any reporting on reflexivity by the author, raises concerns around the external validity of the results. However, Chapman (2002) with a much larger sample, reported similar findings, with participants confirming they were often not aware of HD until much later in life.

*“My mother died at 86. My father died at 79 both really in good health...
we’d never heard of HD even when it came up”*

(Chapman, 2002, p. 356)

In contrast, Cox and McKellin (1999) spoke about how some people were aware of HD much earlier, suggesting that exposure to HD is variable across families, with some seeing the importance of sharing information from an early age.

*“we might have been 16 (pause) 17 . . . when we thought of it and saw that it
was in the family”*

(Cox & McKellin, 1999, p. 630)

1.3.1.2 Striving for the truth: Fact as a foundation?

It is important to establish what factors are associated with a person’s decision to undergo testing. This subtheme attempts to elicit people’s understanding of the testing process and personify the reasons contributing to such an important life choice.

Many of the original themes within the articles selected for review are relevant here. There appears to be a distinct view that predictive testing offered an opportunity to gain significant life knowledge, and to allow people to prepare and make choices

about their future (Anderson et al., 2013; Taylor, 2004; Chapman, 2002; Williams et al., 1999).

Anderson et al. (2013), start their narrative at the point where their participant made the decision to take the predictive genetic test. For the person in question, there was little consideration whether “*it was right or wrong to take the test*” or “*what the consequences would be*”, instead admitting the outcome was something “*she just wanted to know*” after her father became symptomatic. (Anderson et al., 2013, p. 192). Being a well recorded study, with effective use of participant quotes and a sound quality assessment score, findings can be interpreted with confidence. However, as case study, transferability of findings is limited.

While the decision to get tested was less considered for some participants, others reported a much more cogitated approach. Williams et al. (1999), a well reported study, found that ‘at risk’ people sought testing to help make decisions about ‘health care needs’, ‘family’, ‘careers’ and ‘finances’ (Williams et al., 1999, p. 112), illustrated by an at-risk person who had just got married.

“I just got married and I wanted to have my own kids ... and if I did have it, I wanted to start getting financially ready now instead of waiting.”

(Williams et al., 1999, p. 112)

Despite concerns relating to research design and method of analysis, Taylor (2004) reported similar findings, suggesting predictive testing was perceived by all interviewees as an opportunity to acquire significant life information. Furthermore, given the accurate and factual nature of the result, testing was seen to provide a

foundation from which “*subsequent life decisions can be made*” (Taylor, 2004, p. 140).

“I’d like to know [my gene-status for HD] for a fact... you can’t plan anything on fairytales”

(Taylor, 2004, p. 140)

In addition to making life choices while they remained healthy, people also spoke about how the knowledge of their gene status helped them make plans for when they would become unwell and may no longer be able to communicate their desires. One at risk person stated:

“The biggest thing that scares me about all this is that I’m going to get to a point where I’m not able to take care of myself and my biggest fear is I’m going to get put into somebody’s hands that really doesn’t care what happens to me”

(Williams et al., 1999, p. 112)

Chapman (2002) and Williams et al. (1999) also reported participants’ concerns around future generations, especially knowing their children’s risk and potential ramifications that has.

“...if I have it both the boys will have to have the test, but if I don’t they won’t have to have it. If it is negative, the boys will have peace of mind, if it is positive then we will need serious counseling for my sons and grandchildren”

(Williams et al., 1999, p. 112)

Another common theme reported by Chapman (2002) and Sobel and Cohen, (2003) was around familial pressure, with some at risk people reporting difficulties in coping with the uncertainty of potential gene status of at-risk family members.

“When my sister tested positive, my family said I owed it to them to be tested so they might know that there was at least one who was okay.”

(Sobel & Cohen, 2003, p. 51)

In addition to the themes identified above, research suggested that predictive genetic testing could offer some form of relief from the uncertainty associated with the disease. Williams et al. (1999) reported how for some, not knowing their gene status was extremely difficult, with the possibility that they would develop HD being a persistent thought.

“I think it’s been probably the most stressful thing that I have ever gone through emotionally. It has made me question everything, from where I’m at in my career, to all of the choices I have ever made.”

(Williams et al., 1999, p. 111)

Furthermore, predictive genetic testing seemed to offer an escape from constant self-monitoring, with at risk people becoming preoccupied with potential symptoms and uncertainty over their gene status.

“This summer, I had some muscle twitching and I guess I immediately thought this could be HD. So, that’s what brought me to testing, thinking perhaps that this was HD. It’s been a very difficult thing to think about, to

deal with. Part of this is just a sort of terrible anticipation, that's kind of looming over you"

(Williams et al., 1999, p. 112)

1.3.2. Living with the Truth

Two meta-subthemes epitomised 'Living with the Truth': 'Adjusting to loss' and 'Re-establishing of self'.

1.3.2.1. Adjusting to loss

This subtheme relates to reported changes and the associated forfeiture following the outcome of predictive genetic testing, with several studies reporting changes in feelings, attitudes and thoughts about life (Theed et al., 2017; Gong et al., 2016; Hagberg et al., 2011; Schwartz, 2010; Chapman, 2002). Theed et al. (2017) reported how people often attributed psychological distress to HD following a positive test result, with participants believing the experience of physical and psychological difficulties was now 'inevitable'.

"Sometimes I depress myself because sometimes maybe I do think too far ahead...HD just affects so many aspects and that does scare me"

(Theed et al., 2017, p. 6)

Receiving a positive test result also seemingly changed participants' perceptions of their psychological difficulties, with people much more likely to attribute distress to the biological nature of HD.

“you’ve got something to blame it on now’ ... if you’re tired it’s because of the gene, you know, if you get annoyed it’s because of the gene”

(Theed et al., 2017, p. 7)

Confirmation of gene status was also associated with a variety of difficult feelings. The research shows people often embark on the journey of predictive genetic testing in an attempt to gain some clarity and reduce the anxiety of not knowing their gene status.

“I think I’d have been probably down and upset about it if I hadn’t have had the test and just sat in limbo not knowing”

(Theed et al., 2017, p. 6)

However, confirmation of gene status did not always reduce anxiety. Positive test results seemed to replace one type of ambiguity with another (Theed et al., 2017), with participants reporting the uncertain nature of the disease was as anxiety provoking as not knowing they were gene positive.

“No one can tell you what kind of symptoms you’re going to get. I suppose that makes you a bit anxious because you don’t know ...you’ll never know definitely ...it’s not a set path which is really hard”

(Theed et al., 2017, p. 6)

This was further supported by Hagberg et al. (2011), who found for some people in their study, receiving the test results was much harder than anticipated.

“I was maybe a little too, a bit too optimistic/.../it has cost me more than what I thought it would”

(Hagberg et al., 2011, p. 73)

A common theme across the research was the initial shock of a positive result, which often caused elevated levels of distress (Anderson et al., 2016; Anderson et al., 2013; Hagberg et al., 2011; Schwartz 2010; Sobel & Cohen, 2003). This seemed to be followed by a sense of panic and fear, as people started to process what this new discovery meant for them and their future.

“if one hadn’t known then it would have been easier to put one’s head in the sand... it would at least have been 50%.../So it has affected me, and I am very scared/.../I am not like the person I used to be, I have changed”

(Hagberg et al., 2011, p. 73)

The process of predictive genetic testing also seemed to impact people’s quality of life, with some reporting they could no longer enjoy life and others *“struggling to identify anything positive about taking the test”* (Hagberg et al., 2011, p. 73).

Furthermore, a further three participants within the same sample reported feelings of regret ‘several years’ after testing (Hagberg et al., 2011, p. 73). In addition to a sense of hopelessness, feelings of isolation and a lack of peer support was also present for some people following the result (Gong et al., 2016), suggesting a loss of connectedness.

“It can be lonely to know you’re gene-positive”

(Gong et al., 2016, p. 1193)

The sense of loss associated with testing was not only apparent for the individuals at risk, several studies reported how test results often penetrated the wider family, with carriers and non-carriers reporting a sense of chaos and despair (Anderson et al., 2016; Anderson et al., 2013; Taylor, 2005; Sobel & Cowen, 2003).

"If we hadn't been tested we wouldn't be in this mess now,"

(Sobel & Cohen, 2003, p. 50)

The impact of testing also appeared to affect people's close relationships, as people tried to distance themselves from their diagnosis. Anderson et al. (2016), reported how for the person in their study, discovering their status sparked a catalogue of changes in a desperate attempt to escape HD.

"It was a difficult time for me. I had left my family in the desperate search for a new life where Huntington's had no part"

(Anderson et al., 2016, p. 569)

Despite being a case study, findings reported by Anderson et al. (2016) are methodologically sound. Furthermore, both Chapman, (2002) and Gong et al. (2016) reported how being a mutation carrier influenced people's relationships for a variety of reasons including the 'fear of being alone when sick' (Chapman, 2002, p. 74) or worries about other people accepting the consequences of the illness.

"In a way, I feel like I can't split up with my boyfriend, because I don't feel like anybody else would want to be with someone, knowing that they've got HD"

(Gong et al., 2016, p. 1191)

Evidence of loss was not only associated with the immediate aftermath, but also appeared to impact people's thoughts about the future. Gong et al. (2016) reported how the knowledge of gene status for some people in their study had made substantial life decisions like starting a family, more complicated.

“Before I got tested, all I wanted was having kids. But now, whether it happens or not, I’m not gonna be upset either way. Because it’s a win-win situation, having kids or not having kids. Either I have kids and have that joy, or I don’t have kids and don’t have to put somebody else through that”

(Gong et al., 2016, p. 1192)

For some, the loss associated with a positive test result was too difficult, with several papers reporting how for a number of people, suicide seemed like a ‘reasonable alternative to living a life of progressive disability’ (Schwartz, 2010, p. 161; Anderson et al., 2016; Sobel & Cohen, 2003).

“And you know, suicide is something that I think about all of the time because it’s the way I’m going. I’m not going to a nursing home. So, I always have a plan”

(Schwartz, 2010, p. 161)

1.3.2.2 Re-establishing of self

This subtheme represents the process of change and restoration following predictive genetic testing. While the outcome of this process was fraught with challenges for some, other people across the research reported a greater appreciation of life following testing (Gong et al., 2016).

“I think I kind of live life differently. I try to enjoy life, live each day as if it’s the last day. ... I just try to enjoy everything, take everything in and enjoy it”

(Gong et al., 2016, p. 1190)

Scoring well on each of the quality assessment markers, with a good sample size, and clear data analysis and methods, results from the study can be interpreted with confidence. Moreover, Hagberg et al. (2010) despite the smaller sample size, also reported many people within their study (8 out of 10), talked about the positive aspects of testing, with one-person reporting:

“I am going to have as much fun as I can for as long as I can/.../I have become happier and, or one appreciates life more”

(Hagberg et al., 2011, p. 74)

In a similar vein, despite being a complex process, receiving a gene positive result appeared to prompt some people to make important reflections on life and their identity, whether that be in relation to the positive aspects, or the more undesirable factors associated with the disease.

“I think, especially being quite young and getting a result, some of your kind of youthful intoxication and that just kind of goes. But I think I’ve been through a process of—almost like having a mid-life crisis, so I’ve had to sort out—say I’ve only got 10 years to live. Maybe I’ve got longer, you know. Maybe I haven’t. It’s kind of like a process of essentializing my life”

(Chapman, 2002, p. 358)

This sense of reflection appeared to develop into a number of profound changes for many, changes that were closely linked to the theme ‘Urgency to reach milestones’, developed by Gong et al. (2016, p. 1190). A number of people within the research spoke about how the limited number of ‘healthy years’ ignited a desire to expedite the attainment of many life goals, including education, work and starting a family. Similar findings were reported by Hagberg et al. (2002) who described how for some people in their research, testing had spurred them on to do things they have always wanted to do.

“I actually started studying at university...when I got the test results it was like a push to make the best of my life”

(Chapman, 2002, p. 72)

1.3.3. Sharing the Truth

Two meta-subthemes exemplified ‘Sharing the truth’: ‘Do they need to know?’ and ‘Can they handle knowing?’

1.3.3.1 Do they need to know?

This subtheme denotes people’s hesitation in disclosing their genetic status to others and is characterised by the theme ‘Deciding between privacy and openness – how much should we share’ developed by Anderson et al. (2013, p. 193). For some people sharing their story was a way for them to take back some control, rather than worrying what people would say ‘*behind their back*’.

“I want no secrecy, I don’t want people talking about me behind my back. It feels better if I can tell everyone and give my own version. I remember how it

was with my father, with people talking behind his back when he behaved strangely”

(Anderson et al., 2013, p. 193)

In contrast other people were hesitant to share information with others, through the fear of discrimination and not wanting to be judged.

“You have to be careful with who you talk about it because, for example, if you tell somebody and an employer finds out, they can choose not to hire you. Or insurance companies can still - they are technically not allowed, it’s illegal - but they still discriminate against you”

(Gong et al., 2016, p. 1193)

There was also a sense of disparity in relation to disclosing one’s status to close family and friends. While the majority of people shared a sense of responsibility in disclosing their status to loved ones (Gong et al., 2016; Anderson et al., 2013; Hagberg et al., 2011) others, especially those with younger children decided to take a more secretive position.

“My children don’t know anything; I haven’t been able to tell them about it”

(Hagberg et al., 2011, p. 74)

1.3.3.2 Can they handle knowing?

This subtheme, while connected to the one above, explores in more detail the moral dilemmas apparent when considering disclosure. Hagberg et al. (2011), recounted how for some, disclosing their genetic status was often accompanied with difficult

emotions such as guilt, with one person reporting her son's risk being much 'harder to cope with, than her own' (Hagberg et al., 2011, p. 75). Furthermore, there was a sense that by disclosing this information, parents may be somehow limiting the lives of their children by adding a burden and complexity that would be difficult to manage.

“And I have thought about if I had gotten to know all of this when I was young, then how would I have felt about having [children]?/.../Somewhere in it all I would have felt limited/.../Let them have children if they want, all in their time, sooner or later they will find out about this anyways and then I can tell them”

(Hagberg et al., 2011, p. 74-75)

Williams et al. (1999), on the other hand reported how children at risk of developing the disease from a parent also shared similar worries, not wanting them to feel guilty about their own fate.

“My brother and sister and I have decided we're going to tell Dad that our results are negative no matter what they are, because we don't think he could handle thinking that he gave that to one of his kids”

(Williams et al., 1999, p. 112)

Finally, the thoughts around disclosure and its effects, also appeared to be represented in thoughts about future relationships, with concerns about how or if a potential intimate partner will deal with such information.

“The biggest question is when or if or how do I tell someone that I want to date about Huntington’s disease and being tested. ... just in general telling people, it’s very tough, because you don’t know whether they are going to judge you, and how they are going to react”

(Gong et al., 2016, p. 1193)

1.4 Discussion

This aim of this systematic review was to produce a meta- ethnographic synthesis of qualitative findings relating to people's lived experiences of predictive genetic testing for HD. A total of 11 articles were included, and analysis led to the development of three meta-themes, 'Facing the truth', 'Living with the truth' and 'Sharing the truth'. There were commonalities within the articles, indicating, at least in part, a 'reciprocal translation' (Atkins et al., 2008; Purc-Stephenson & Thrasher, 2010). However, several dissonances were also present within the data, meaning it was not possible to provide a uniform account of people's experiences.

1.4.1 Summary of findings

Despite variations in how people come to discover their risk of HD (Schwartz, 2010; Cox & McKellin, 1999), many appeared to view testing as an opportunity to gain significant life knowledge (Anderson et al., 2013; Taylor, 2004; Chapman, 2002; Williams et al., 1999). For some, testing provided a sense of relief from the ambiguity of not knowing and provided an escape from constant preoccupation with potential signs and symptoms (Williams et al., 1999).

In terms of living with the knowledge of their gene status, a variety of responses were witnessed. Awareness of gene status appears to be linked to a direct change in beliefs, attitudes and thoughts. While some changes were associated with anxiety and worry, others were related to more positive aspects, especially in relation to outlook on life (Gong et al., 2016; Hagberg et al., 2011; Chapman, 2002). Testing seemed to provide an incentive to make the most of a limited number of 'healthy'

years, accumulating in sense of urgency to reach significant milestones. In contrast, some findings point to an awareness of gene status having a somewhat constraining effect, making relationship and reproductive decisions more difficult. The process of predictive genetic testing did appear to have a great emotional impact, with feelings of panic, shock, and fear permeating across studies (Anderson et al., 2016; Anderson et al., 2013; Hagberg et al., 2011; Schwartz 2010; Sobel & Cohen, 2003; Chapman, 2002). Despite themes of tolerance and acceptance developing for some, others reported finding it difficult to accept the knowledge testing brought, resulting in a sense of hopelessness and isolation (Gong et al., 2016; Anderson et al., 2016; Anderson et al., 2013; Hagberg et al., 2011). At its worst, knowledge of genetic status resulted in a sense of chaos and despair, with several people in various studies reporting pervasive suicidal thoughts, and suicide attempts (Anderson et al., 2016; Schwartz, 2010; Sobel & Cohen, 2003)

1.4.2 Relation to previous literature

Most research within this area consists of quantitative studies, reporting little or no significant psychological impact (Decruyenaere et al., 1996; Broadstock et al., 2000; Meiser & Dunn, 2000; Timman et al., 2004; Crozier et al., 2015). This review adds to our current knowledge by recounting a variety of qualitative papers reporting themes associated with distress and difficulty (Hayden & Bombard, 2005; Schwartz, 2010; Hagberg et al., 2011). Furthermore, findings here highlight a variety of emotional responses, suggesting that standardised psychological measures of distress may not be sensitive enough to capture such experiences (Chapman, 2002; Hagberg et al., 2011; Crozier et al., 2015; Gong et al., 2016; Theed et al., 2017).

In relation to long term outcomes following testing, previous quantitative accounts have reported no significant lasting psychological impact (Timman et al., 2004). Akin to feelings associated with loss and adjustment by Kubler-Ross (1969), tolerance and acceptance did appear to develop for some people within this review. However, others reported finding it difficult to accept the knowledge testing had brought, resulting in a sense of hopelessness, isolation and in some cases suicidal ideation (Gong et al., 2016; Anderson et al., 2016; Anderson et al., 2013; Hagberg et al., 2011).

The Common-Sense Model of self-regulation of health and illness developed by Leventhal et al. (1998) highlights how illness representations, or cognitions, are used to appraise the threat of disease in relation to its cause, controllability and consequence over time. Given the uncontrollable and fatal consequences associated with HD, the variety of reactions seen here are unsurprising, as it is likely that a diagnosis of the condition would be appraised as highly threatening and distressing. With this in mind, more contemporary models such as the Dual Process Model of grief developed by Stroebe & Schut (1999), may more accurately represent the complex and intertwining process of loss represented here.

Despite the difficulties evident within the findings several studies reported some participants taking affirmative action's following testing. This was largely in relation to outlook on life and a tendency to live life more in the moment, resulting in people seeking out experiences that they may not have prior to testing (Chapman, 2002; Hagberg et al., 2011; Gong et al., 2016).

1.4.3 Limitations

This review focused on people's experiences of predictive genetic testing within Western, English speaking countries. Whilst a variety of countries were included, and experiences appeared seemingly consistent, it is uncertain whether the current findings are transferable to other non-English speaking countries, given differences in beliefs, values and attitudes towards illness, together with potential divergences in access to healthcare and social support systems.

Steps were taken to ensure a methodologically rigorous (e.g. consistent with other meta-ethnographies), transparent (e.g. by using appropriate quotations) and consistent (e.g. by making references to original themes) review was conducted.

Search terms could have been expanded to include the term 'Huntington's Chorea', a term that despite its age may have elicited further relevant research.

To provide context to the analysis, the author's subjective experiences of HD were made explicit (Walsh & Downe, 2006). However, as with many qualitative syntheses, it is likely that the results of the review were influenced by the author's interpretations (Al-Natour, 2011; Shenton, 2004). As such, it would have been beneficial to have collaborated with co-authors for all articles during data extraction and analysis, to further enhance the validity of the interpretations.

1.4.4 Clinical implications

Several studies highlighted how the experience of testing resulted in significant emotional distress (Sobel & Cohen, 2003; Schwartz, 2010; Anderson et al., 2016).

While the impact of such knowledge is difficult to gauge, it is imperative that genetic counsellors have a good understanding of ego strength prior to the testing process. Furthermore, they must discuss the complex picture of what it is like to undergo predictive genetic testing and live with the knowledge of the outcome, as although results may provide certainty regarding status, uncertainties, particularly for those testing positive, are likely to remain. By highlighting a variety of experiences, the results of this review, may provide an insight into why the minority of people at risk of HD (<20%), decide to undergo testing. As such, previous findings (i.e. absence of significant psychological impact), may not accurately represent the full and complex picture. Given the findings of this review, it is difficult to recommend the continued use of standardised psychological measures to assess distress for clinical purposes. Alternatively, it may be beneficial for services to offer follow up genetic counselling and support to help monitor the effects of testing.

1.4.5 Future research

It would be useful to explore whether the results of this review are in line with people's experiences from non-western countries. As such, future research could seek to conduct a review of literature exploring people's experiences of predictive genetic testing for HD in varying geographical locations.

Given the range of experiences witnessed within this review, further research exploring effectiveness of standardised psychological measures of distress compared to more specific measures for HD (e.g. Unified Huntington's Disease Rating Scale - Witjes-Ané et al., 2002), would be beneficial. This could help inform future practice by producing a more accurate and coherent picture of potential psychological

consequences of testing.

Finally, research exploring what factors and/or interventions might help facilitate adjustment to living with the knowledge of gene status, together with what may inhibit this, would help generate further understanding of people's experiences of genetic testing for HD.

1.5 Conclusion

This was the first qualitative systematic review of the literature exploring people's experiences of predictive genetic testing for HD. While previous findings suggest little psychological impact, the majority of participants within this review, did report significant cognitive, emotional and behavioural changes. It is therefore important for healthcare professionals and genetic counsellors to be mindful of the potential implications of testing, together with possible pitfalls in the use of standardised measures of psychological distress with this population.

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Chapter Two

Empirical Paper

Young people's lived experiences of cancer: An Interpretative Phenomenological Analysis

This chapter was prepared for submission to The British journal of Health Psychology, Appendix F provides detailed author guidelines from this journal. The word count for this chapter, excluding abstract, figures, tables and references, is 7,977

2.0 Abstract

Aim: Being diagnosed with cancer can be a traumatic and life changing event at any life stage. However, receiving a diagnosis during adolescence and young adulthood carries extra significance given the complicated task of navigating a variety of milestones. There is currently a dearth of research exploring young people's lived experiences of cancer in the UK. The present study aims to build on existing research by using IPA to explore the lived experiences of young people aged between 13-24 years.

Method: An interpretative phenomenological analysis (IPA) was undertaken with six young people (13-24 years) with a recent diagnosis of cancer. Semi-structured interviews were audio recorded, transcribed and analysed in line with the IPA methodology.

Results: Three superordinate themes emerged from the data: 'A natural injustice', 'Get Ready for battle: Cancer as an adversary to youth' and 'The upside down: A parallel universe'.

Conclusions: Young people's experiences of being diagnosed and treated for cancer are considered. Clinical and service implications, together with areas for future research are discussed.

Keywords: *Adolescence, Young adults, Young people, 13-24, diagnosis, treatment, cancer, Phenomenological, IPA*

Abstract word count: 174

2.1. Introduction

2.1.1 Background

Being diagnosed with cancer can be a traumatic and life changing event, with people's beliefs about life, themselves, and their future often being challenged (Macmillan Cancer Support, 2006). Although the majority of cancer patients experience a common set of life disruptions (Rowland, 1990), theories of human development suggest the way in which people experience them will differ. Research has suggested that people can focus on different issues, attaching different levels of significance to different aspects of their experience depending on the age they were diagnosed (Zebrack, 2011). Furthermore, research has shown that receiving a diagnosis during adolescence and young adulthood carries extra significance given the complicated task of navigating a variety of emotional and developmental milestones (Corbeil, Laizner, Hunter, & Hutchison, 2009).

2.1.2. Cancer in young people

Every day in the United Kingdom, seven young people (13-24 years) receive a diagnosis of cancer (Teenagecancertrust.org, 2018), and with approximately 310 deaths each year, it is the leading cause of death from disease for young people in the UK (Cancer Research UK, 2015). While definitions of adolescence and young adults vary, this research will focus on those aged 13-24 years, in line with the Teenage Cancer Trust's classification. Despite such a broad age range, there are few empirical studies exploring the subjective personal experience of young people during this time (Woodgate, 2005; Taylor, Gibson, & Franck, 2008). A meta-synthesis published by Taylor, Pearce, Gibson, Fern, and Whelan (2013), found that

much of the research exploring young people's experiences of cancer has focused on parental or caregivers' perspectives, with very little qualitative data from the young people themselves. Furthermore, the relatively small amount of literature that has started to concentrate on the experiences of those affected, has sought young people's views of hospital facilities, treatment environments, social support and coping strategies (Lockhart & Berard, 2001; Mulhall, Kelly, & Pearce, 2004; Cassano, Nagel, & O'Mara, 2008; Wicks & Mitchell, 2010).

2.1.3 Adolescence and young adulthood

Adolescence and young adulthood are arguably the most complex developmental stages in a person's life and are often marked by a plethora of changes in social, cognitive and emotional development (Arnett, 2000). The transition from childhood to adulthood is often fraught with challenges, with adolescents and young adults facing a range of tasks including establishing personal identity, seceding from parents/caregivers, managing intensifying relationships with peers and/or partners, exploring sexuality and gender identity, together with navigating potential future decisions such as career, education and family (Eiser & Kuperberg, 2007).

Consequently, cancer related issues such as untimely confrontation with impermanence and death, changes in physical appearance, increased dependence on caregivers, disruptions in social life and challenges in school and/or employment have been shown to be acutely distressing for young people (Albritton & Bleye, 2003; Shama, 2007).

2.1.4 The impact of cancer on young people

From the Platt Report examining the welfare of young people in hospital (Platt, 1959), to more recent NICE guidance published to help improve outcomes for

children and young people with cancer (NICE, 2014), research and policy has begun to stipulate the unique position and needs of young people with cancer. A mixed method study by children's charity CLIC Sargent (2017) used telephone and Skype interviews with five young people and gathered survey data from a further 149 to explore the implications of living with cancer as a young person. The majority of respondents (79%, n=119) reported their cancer diagnosis had an impact on their overall wellbeing, with 70% experiencing depression, and 99% reporting episodes of low mood. The study also highlighted how 90% of young people in the sample experienced anxiety, with 42% of those reporting panic attacks during treatment (CLIC Sargent, 2017).

Grinyer (2007) examined the effect cancer had on the lives of 40 young people aged between 16-24, through a mixture of in depth qualitative interviews and written narratives. Data was analysed using a qualitative approach known as 'transcendental realism' (Miles & Huberman, 1994) and consists of three main components; data reduction, data display and conclusion drawing. Results found three key areas: the disruption of life trajectories, the loss of independence and the setting of care. Within these, several important aspects of young people's lives were also shown to be affected, including education, careers, life plans, friendship networks, appearance, sexuality and fertility. Such findings have been further supported in work by Lewis, Somers, Smith and Kerridge (2013), who through the use of thematic analysis found young people's development was often arrested by their cancer experience, increasing their dependency on parents and complicating the process of making new relationships and gaining autonomy.

2.1.5 Lived experiences of young people with cancer

Hedstrom, Skolinb, and Essena (2004), investigated the lived experiences of 23 young people with cancer in relation to: receiving a diagnosis, undergoing treatment and being admitted to hospital. Data was gathered using semi-structured interviews and analysed using content analysis. Findings demonstrated young people were subject to a range of distressing experiences including alienation from peers, altered physical appearance and coping with the possibility of dying. Positive experiences included relationships with staff and being well cared for. More recently a study by Gibson et al. (2016), sought to find more information about how young people experience cancer and its treatment. Longitudinal video diaries of 18 young people aged 11-25 were analysed using qualitative content analysis. Four main themes emerged: treatment and relenting side effects, rehabilitation and moving on with life, relapse and coming to terms with dying.

2.1.6 Rationale

The emergence of qualitative and mixed methods enquiry over the past ten years has provided some knowledge surrounding the impact a cancer diagnosis can have on the lives of young people. Recent reports by CLIC Sargent (2017) have highlighted the relationship between physical and mental health among this population, revealing most young people surveyed, experienced some form of mental health difficulties whilst undergoing treatment.

However, given the majority of research has been gathered in conjunction with parents and healthcare professionals, there is an absence of subjective accounts from young people themselves. Furthermore, despite the use of qualitative methods such

as thematic and content analysis shedding light on common themes associated with young people's experiences, they are singular in focus. Additionally, in the case of content analysis, themes are not explicitly taken from the data itself, but gathered in conjunction with predetermined structures which are placed on the data set prior to the investigation, thus limiting the scope of what can be explored (Elo & Kyngäs, 2008). The current study therefore aims to fill these gaps by using Interpretative Phenomenological Analysis (IPA) to gain a detailed account of what it is like to live with cancer as a young person within the UK. By adopting this approach rather than qualitative methods seen in previous research, it is hoped that a more robust understanding of lived experiences will be generated.

2.1.7 Research Aims

Whilst literature exploring the impact of cancer on young people has increased, there is a dearth of research that examines young people's lived experiences of cancer. The aim of this study is to build on existing research by using IPA to explore the lived experiences of young people aged between 13-24 years. To ensure a detailed and recent account of personal experience, this project will focus on individuals who have been diagnosed within the last 6-18 months. The study aims to address the following question:

What are the lived experiences of young people (aged 13 to 24) who have recently been given a diagnosis of cancer?

2.2. Method

2.2.1 Design

2.2.1.1 Qualitative approaches

Qualitative research is an ‘umbrella’ term used to describe a variety of approaches that adopt a social inquiry into the way people make sense of and interpret their world (Atkinson, Coffey, & Delamont, 2001). This study adopted a phenomenological approach to explore the lived experiences of cancer amongst young people.

2.2.1.2 Interpretative Phenomenological Analysis

This research used Interpretative Phenomenological Analysis (IPA; Smith, 1996; Smith, Flowers, & Larkin, 2009). IPA is “*committed to the examination of how people make sense of their major life experiences*” (Smith, Flowers, & Larkin, 2009, p. 1) and as such was consistent with the research aim. By recognising that every methodological stance can create reality as well as explain it, this approach positions participants as the experts of their own experiences, focusing on ensuring people’s experiences are expressed in their own terms, i.e. from participants’ frame of reference. Therefore, IPA endeavours to give voice and make sense of experiences, utilising a bottom-up approach that avoids creating theories (Larkin & Thompson, 2011; Smith et al., 2009; Taylor & Bogdan, 1998). IPA also recognises the role of the researcher when collecting information, adopting the term ‘double hermeneutic’ to acknowledge how the researcher’s own views and or experiences may influence data analysis (Smith et al., 2009).

2.2.1.3 Researcher's position

Acknowledging the researcher's position and recognising the challenges of remaining impartial and objective is fundamental in the validity of research. As such, author reflexivity is key (Harris, 1976; Smith, 1983). As Smith et al. (2009) assert, experiences are brought to the research; and the author's identification as a white, middle-class male with a recent experience of cancer within their family, will somewhat impact the interpretation of the data. A bracketing interview was conducted in addition to measures of self-reflexivity (journal and interview logs) to consider the stance in which the author relates to and interprets experiences of difficulty and illness (Finlay, 2008). Initial reflections included thoughts around resilience and the importance of being able to voice individual experiences regardless of age.

The researcher utilized an interpretivist position. Interpretivists believe that society operates differently from the natural world and believe reality is subjective. This approach is less interested in universal meaning or commonality, but instead focuses on how a person develops their own unique views based on their individual experiences (Willis, 2007). Rather than measuring phenomena, interpretivist research attempts to gain an insight into what life is like for a person and is congruent with the researcher's own personal epistemology.

2.2.2 Participants

2.2.2.1 Inclusion and Exclusion Criteria

Sample size within IPA research is often contextual. In line with guidance developed by Smith et al. (2009) and to reduce the risk of oversaturation of the data, a small

sample of participants was selected. To ensure homogeneity of the sample, the project enlisted a range of inclusion and exclusion criteria. Young people aged between 13-24 years were eligible to participate within this project, with people falling outside this age range being excluded. To ensure a recent account of personal experience, people between six and 18 months post-diagnosis and still undergoing treatment were included. Participants were excluded from the project if they were unable to speak English or had been identified by clinical staff as being too unwell to take part. To gain an insight into the lived experiences of this age range and given the lack of previous research, both male and female participants were included (Taylor et al., 2013). Table 2.1 provides a summary of the inclusion and exclusion criteria.

Table 2.1 Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Age	≥ 13 Years - ≤ 24 Years	< 13 Years - > 24 Years
Onset	≥ 6 Months - ≤ 18 months	< 6 Months - > 18 Months
Gender	Male/Female	n/a
Language	English	Non-English
Stage	Undergoing Treatment	Complete Remission/Palliative care regime

2.2.2.2 Participant Characteristics

Six young people participated in the study. Table 2.2 provides demographic information for the participants; pseudonyms have been used to ensure anonymity.

All participants were undergoing treatment when recruited. Due to logistical reasons beyond the author's control, the interview for one of the participants took place two weeks after their final treatment. The young person in question expressed a desire to still participate in the project and given the immediacy of their treatment completion it was felt their account would still be relevant and appropriate. One participant in the sample sadly died since taking part in the study. Given informed consent was obtained prior to their death, and in line with the Health Research Authority (HRA) guidance (See appendix G), their account has been included within this project.

Table 2.2 Participant Characteristics

Participant (pseudonym)	Age	Gender	Date of diagnosis	Form of treatment
Abigail	16	Female	February 2017	Chemotherapy Radiotherapy
Adam	20	Male	January 2017	Chemotherapy Radiotherapy
Alesha	24	Female	July 2016	Chemotherapy Surgery
Claire	14	Female	June 2017	Chemotherapy Surgery
Jack	19	Male	November 2016	Chemotherapy Surgery
Joe	23	Male	January 2017	Chemotherapy Stem Cell Treatment

2.2.3 Procedure

2.2.3.1 Ethical procedure

Given the vulnerable nature of the people taking part in the study, due care and diligence to ethical standards were imperative. The research was first approved by Coventry University on 11th May 2017 (Appendix H), and further approval was granted by a National Health Service Ethics Committee, (REC reference; 17/WM/0235) on 24th July 2017 (Appendix I). The project fully adhered to the British Psychological Society's guidelines (BPS, 2010), recognising the importance of voluntary participation, assent and consent, as well as people's rights to anonymity and confidentiality.

2.2.3.2 Materials

A semi-structured interview schedule was designed and utilised (Appendix J) in accordance to the guidance set out by Smith et al. (2009). A semi-structured approach was selected as it provides guidance of the topic under investigation, whilst also ensuring a degree of flexibility for the participant and researcher, allowing other potentially salient experiences to be explored.

2.2.3.3 Recruitment

In recognition of the difficulty accessing the population due to their age and condition, this project utilised a purposive sampling method. Purposive sampling is a type of non-probability sampling that allows the researcher to select participants based on certain characteristics. On several occasions throughout the project the researcher met with the clinical team at two large regional cancer centres, one of which was based at a children's hospital. During the recruitment period (September

2017 – February 2018), 22 participants were identified as eligible for participation. Participants and if necessary their parents/legal guardians were sent an information sheet (Appendix K, L, M) and were asked to contact the researcher or clinical team to express interest in taking part. A total of six young people agreed to be contacted by the researcher, all of whom agreed to take part.

2.2.3.4 Interview Procedure

Interviews took place between October 2017 and March 2018. The location of the interview varied and included the participants' home ($n = 3$), university premises ($n = 1$) and the hospital ($n = 2$). Interviews lasted between 55 and 208 minutes ($m = 96$ minutes) and were audio recorded. Participants were asked to review the information sheet again prior to starting the interview, following which assent/informed consent was obtained (See appendix N, O, P). Given the aim of the project, there was the potential that those involved may find participation distressing and or difficult. As a result, the option to take regular breaks, stop the interview or withdraw from the study at any point prior to data analysis was emphasised to participants. In addition, with the young person's consent a letter detailing their involvement was sent to their GP. Time was allocated at the end of the interview for participants to reflect on the process of taking part. A debrief document containing information on local support services was also provided (Appendix Q). Participants were reminded that they had two weeks following the interview during which they could withdraw from the study, after which transcription and data analysis would be underway.

2.2.4 Analysis

Following completion of the interviews, audio recorded interview data was transcribed as proposed by Smith et al. (2009), with identifying information being omitted or substituted as necessary. Following transcription, data was analysed in line with the procedure set out by Smith et al. (2009). Firstly, the researcher immersed themselves within the data set, by reading and rereading the first transcript. The second stage entitled “initial noting” examined semantic content and language within the data to produce a descriptive summary of the participant’s feelings and concerns. Data was then analysed in an interpretative way and the focus shifted to establishing meaning behind the words themselves. The researcher then used this information to develop a range of emergent themes within the data, which were then analysed for commonalities and relational aspects. The researcher then applied the above steps to the remaining transcripts before moving to the final stage, which involved identifying patterns and connections across the data as a whole. A detailed account of the IPA analysis procedure, examples of extracts from coded transcripts and a map of emergent and super ordinate themes can be found in Appendix R (Table 2.4), Appendix S and Appendix T respectively. Furthermore, the researcher maintained a reflective journal at each stage of the analysis in order to aid reflexivity.

2.2.4.1 Validity and credibility

Data authentication was achieved with a second member of the research team who assessed and commented on emerging themes. Validation of the final superordinate themes, content, linguistic and conceptual coding were also shared. Next, in order to

ensure sincerity of the findings, participants were contacted to ensure the outcome was an accurate and authentic representation of their account (Mays & Pope, 2000).

2.3 Results

Following the completion of data analysis, three superordinate themes emerged: ‘A natural injustice’, ‘Get ready for battle: Cancer as an adversary to youth’ and ‘The upside down: A parallel universe’. Within each superordinate theme lay several subordinate themes, see Table 2.3. Convergence and divergence amongst the narratives are considered throughout the results.

Table 2.3 Superordinate and subordinate themes

Superordinate theme	Subordinate theme
A Natural Injustice	1) Refuting the diagnosis: “I just didn’t believe them”
	2) “Why me”: Making sense of the senseless
	3) Incarceration: “You’re like kind of like stuck there”
Get ready for battle: Cancer as an adversary to youth	1) Arrested development
	2) A new perspective
	3) “The fight of the mind”: Me vs My Body
The Upside Down: A Parallel Universe	1) “Out of the loop”
	2) In your own world: “You don’t see girls with bald heads everywhere”
	3) Finding a safe harbour

2.3.1 A Natural Injustice

All participants spoke to the invidious position of being diagnosed and treated for cancer. From battling disbelief to trying to make sense of this cruel and unapologetic disease, most young people reflected on the iniquitous and untimely task of being diagnosed with cancer as a young person. This superordinate theme consists of three subordinate themes, ‘Refuting the diagnosis: “*I just didn’t believe them*”’, “*Why me*”: ‘Making sense of the senseless’ and ‘Incarceration: “*You’re like kind of like stuck there*”’.

2.3.1.1 Refuting the diagnosis: “*I just didn’t believe them*”

Four participants reflected on their experiences of struggling to come to terms with having cancer. This often emerged soon after the diagnosis and was intensified by the initial shock of receiving the news.

“I just didn’t believe them, I just said straight to them, I just said to them, my first words was you’re lying, you’re lying to me”

(Joe, 216-219⁵)

Joe described his initial disbelief when he was told he had cancer. Describing how he started “*punching the bed*” because he couldn’t comprehend what was happening demonstrates the level of anger and frustration he felt within this moment. Abigail also reflected on how being confronted with her diagnosis was extremely difficult, recalling how she “*did almost faint*” when the doctor told her she had cancer.

⁵ Lines numbers within transcript

This sense of disbelief and refutation was not static, instead reoccurring over the course of most young people's cancer journey. Alesha, Joe and Abigail reflected on how difficult it was to come to terms with what the diagnosis now meant for them and their lives. This was often compounded by their expectations of "*being a cancer patient*" through what they had learnt via their own individual experiences and what they had seen within the media. Alesha spoke about how cancer was often portrayed as "*something scary*" and "*dangerous*" and how it was hard to accept that she will now be "*going through it*" herself. Abigail also reflected on images she saw of cancer patients with "*bald heads*" and "*looking all poorly*", which left her with a sense of worry and disbelief demonstrated by her use of the phrase "*oh my god, that's me now*".

Conversely, Adam, Jack and Claire did not report the same emotional intensity in their reactions, but instead reflected on how they employed distraction as a way of minimising or refuting what was happening. An example of which came from Claire who described how she went home and started reading a new book following her appointment:

"I had only just started reading the book, so I just sort of went straight into the book and sort of forgot about it"

(Claire, 128-129)

The difficulty in coming to terms with a diagnosis of cancer is emphasised here with Claire trying to lose herself in her book and forget about the current situation. Diverting her attention suggests a possible need to take stock of the situation, confirmed by her statement "*I think it might have been a distraction*".

2.3.1.2 “Why me?” Making sense of the senseless

Several participants reflected on the unjust nature of being diagnosed with cancer, expressing difficulty in understanding their diagnosis. This was often accompanied by feelings of frustration and an ardent desire to try and make sense of their situation. For example, Alesha talked of how she was frequently consumed by the thought that she “*did something wrong*” and that somehow her diagnosis was a form of “*karma*” coming back to her. Similarly, Joe reflected on his past life decisions, wondering if previous actions had contributed to his current situation, “*I’d go out and drink every weekend, and at the start I thought that might have been a reason why I was in here*”. In contrast, Claire spoke about how she tried to remind herself that cancer is a disease that can happen to anyone, “*I just sort of, just kept telling myself it happens to a lot of people*”.

In addition to self-attribution, Alesha and Joe questioned the fairness of their diagnosis, struggling to accept their position at this stage in their life. For Alesha, the difficulty lay in the fact she had just got married and had a child, “*why did I get this chance to give birth and to get married and then all this happen*”. Joe expressed an anger and frustration towards his position, questioning why he was having to live with this disease when other people didn’t.

“I thought like, why me (pause) like there's people out there (crying) ok I not sure know if you want to hear it on here, but do drugs, do drugs every day, do things out of the ordinary, why haven't they got it”

(Joe, 641-645)

In contrast, the remaining participants did not express such concerns, instead alluding to how the diagnosis offered a form of relief by providing them with a sense of certainty. Jack spoke about how for him, confirmation of his tumour allowed him to make sense of his ongoing difficulties, which up until that point were perplexing:

“I was ... I was glad to know what it was to be fair ... because that meant that I am gonna ... were gonna be able to try and sort it”

(Jack, 285-287)

Many participants spoke about their desire to understand more about their condition and treatment. This zealous attitude was often linked to a sense of mastery and seemed to provide a way for young people to try and take control of and engage with their condition:

“Obviously, I had a look at what it was, because they told me I can't remember what the name of it was, but I had a look at what that was and like how long it would take to go through all the treatment”

(Adam, 207-211)

Conversely, some young people took a more secondary approach putting their faith in the medical team and treatment. For example, Joe expressed his desire not to know about his current position and treatment options, stating *“not knowing the result means that there might be a chance”*. This was supported by Claire, who despite being *“worried”* about the chemotherapy, just wanted to *“get on with it”*.

2.3.1.3 Incarceration: “You’re like kind of like stuck there”

Whilst the young people consented to treatment, the effects of being subject to such lengthy and at times “*harsh*” regimens was something that they all denoted as “*difficult*”. Abigail described how she was “*forcibly*” taken away from her normal life, while Adam, Claire and Jack expressed how they were “*shocked*” by the length of treatment, “*having*” to stay away from home for prolonged periods. Such restrictions lead to many young people experiencing a loss of freedom, akin to incarceration, as epitomised in Jack’s observation:

“I don’t want to call it like a prison because it’s not…… But it kind of is... you’re like kind of like stuck there... you can’t just say I am going out... I’m going up town...”

(Jack, 1329-1335)

Another striking observation that demonstrated the restrictive nature of cancer treatment came from Joe, who was often confined to the boundaries of the hospital during treatment:

“they said if I was to go outside and get a cold I could die, you know no second chance like, that’s why I have to stay in here...”

(Joe, 368-371)

In addition to the constraints of the hospital environment, many of the young people explained how their home lives were also impacted because of treatment. Such reflections were often accompanied by feelings of antipathy and frustration, with several young people speaking to the sadness such restrictions inflicted on their lives. Alesha spoke about how she would constantly get “*infections*” which resulted

in her spending more time in hospital away from her son. Joe emotionally described how his treatment had stripped away previous life pleasures, commenting on how he was no longer “*allowed*” takeaways, and instead relied on a restricted diet due to the risks of “*food poisoning*”. In addition to risks to their physical health, treatment also restricted the behaviours of many participants. Joe spoke about how he could no longer “*go out*” as he did not have the “*strength*”, while Alesha commented on how treatment meant she could no longer “*breastfeed*” her son, leading her to question her identity as a mother.

This sense of constraint and confinement also seemed to penetrate the simplest of events such as spending time with friends, demonstrated here through Claire’s emotional account of a recent visit to her friend’s house:

*“I went over to ***** house, and they went out in the snow and things. That was very upsetting, cos I love the snow. And this year it came, I couldn't go out in it”*

(Claire, 707-710)

Conversely, Adam took a more stoic approach when talking about his experiences. Describing how spending increased amounts of time on his “*own*” was part of the treatment and something he had come to accept.

2.3.2. Get ready for battle: Cancer as an adversary to youth

All participants reflected on how their experiences of cancer often felt like an internal and, at, time’s external ‘*battle*’. Participants spoke to a range of inherent challenges associated with living with cancer as a young person, from navigating the

course of treatment, to trying to uphold a sense of self that remained separate from the disease and protected their identity as a young person. This superordinate theme includes three subordinate themes, ‘Arrested Development’, ‘A new perspective’, and “‘*The fight of the mind*’: Me vs My Body’.

2.3.2.1 Arrested development

Many of the participants discussed the impact of receiving a cancer diagnosis at such a crucial developmental stage: speaking to the loss of her newly established “*independent*” self, Abigail explains how cancer had made her more reliant on other people:

“I was kind of drifting away a little bit, going to my friends and kind of gaining independence and doing things by myself, but like because I couldn’t do anything by myself, I had to rely on family...”

(Abigail, 714-717)

Age was something that all participants connected with, however for the two older people in the sample, returning to a more dependent state often had implications for their partners, as well as their wider family. Losses here were linked to young people’s identity as partners and parents, highlighted by Alesha.

“so basically, he was like the mother to our son... it was really hard for me”

(Alesha, 103)

In addition to the loss of new found independence, living with cancer as a young person had other unique consequences. Many of the participants here reflected on

how their cancer diagnosis forced them to start engaging in more matured and often complicated life decisions, they had not previously contemplated. Claire, the youngest person in the sample spoke about how her diagnosis meant she had to “grow up” and make decisions “*you didn’t think you’d have to make*”, which reached a crescendo when she chose to have an ovariectomy.

“I talked to Mum about it. I don't want children but then it's the option if I want them when I'm older. It's not something you think about at my age”

(Claire, 669-671)

In addition to more practical life choices, young people reported how being diagnosed with cancer lead them to consider more existential events, such as impermanence and death, epitomised here by Abigail’s reflections:

“I went to my friend’s funeral that passed away, so also that kind of set something off, something I need to think about, and watching like her friends carry on with life without her, is that going to happen to me, is that going to, yeah its quite like a lot to think about”

(Abigail, 672-678)

Although difficult to consider, Abigail’s reflections epitomise one of the most feared consequences of being diagnosed with cancer. This expression also highlights how for Abigail, the thought of life carrying on without her was quite “*overwhelming*”.

2.3.2.2. *A new perspective*

In addition to delaying aspects of development, implications of a cancer diagnosis at this age were linked to a change in young people's perspectives and outlook on life. Many of the young people spoke about how their view on life, and what was important had changed. For Joe this resulted in an ardent desire to start making more "memories", while Abigail spoke about the desire to travel and experience more things.

"I guess like travelling maybe, I don't know, saying that I have achieved things like kind of, like, I think I am a lot more, like experiences are a lot more valuable than possessions"

(Abigail, 838-840)

Another distinctive concept of living with cancer as a young person emerged from the participants shift in understanding and appreciation of 'life'. Stories from the young people suggested a new found responsibility to live life, and be appreciative for the time they had. For Jack, cancer made him "*more grateful for life*" leading him to take his time on earth "*a lot more seriously*". Such growth and discovery was echoed by Claire, whose experiences resulted in the creation of a "*bucket list*" to help her focus on the things she felt were most important.

Whilst these changes may have provided a sense of growth and mastery for some young people in the sample, reflections were not always positive. Depictions indicating the costs of such an early evolution were scattered throughout the narrative, with young people talking about an expedited coming of age that limited their number of "*younger*" years, as exemplified here by Joe's statement:

“Yeah, I feel like I'm in a 23-year-old body, but I've got a 50-year-old brain do you know what I'm trying to say?”

(Joe, 615-617)

With a crack in his voice, and a depleted look on his face, Joe's statement highlights how despite affording a new found perspective, cancer can drag young people into a development stage far beyond their years, forcing a responsibility and sensibleness whilst eliminating the naive and unworldly innocence of this life stage.

2.3.2.3 *“The fight of the mind”: Me vs My Body*

Deep within the narratives shared by each young person lay a declaration to *“fight”* and overcome their condition. Inherent to this encounter was the notion that cancer was something that was separate to them, with many participants referring to how their mind was OK, but their body was not.

“my body was saying something else...I had tubes everywhere...machines everywhere my body was not fine...but my mind was fine...”

(Alesha, 442-445)

This sense of splitting seemed to protect the young people's sense of self, allowing some distance from them and the cancer. Furthermore, adopting this mind set seemed to increase their sense of control and omnipotence in what was often an uncertain and uncontrollable situation, as typified here by Abigail:

“I wanted to gain some of that control back...because everything else was so uncontrollable”

The importance of adopting a positive and optimistic mindset during treatment was also something shared by all the young people. Jack spoke about the importance of not looking at the “*worst bits*”, instead focusing on what “*positive*” you can take from the situation. Joe also spoke about the importance of having “*positive thoughts*”, which for him served to sustain a sense of “*hope*” about the future. Further to changing her “*mind*” and focusing on “*seeing the positive*”, Alesha spoke about the importance of surrounding herself with “*positive people*” who have “*seen other people going through it*” in order to help “*encourage*” her to keep going.

For most young people, adopting a more encouraging mindset was vital to help them move forward. Furthermore, several participants spoke about how this shift in perspective came from within, personifying a resilience and strength that was integral to their identity as a young person.

2.3.3 The upside down: A parallel universe

This superordinate theme speaks to the unique experiences the young people underwent as a result of being a “*cancer patient*”. It encompasses a felt sense of being transported in to a new world, which at times led participants to feel separate from those around them. Three subordinate themes are discussed: ‘Out of the loop’, ‘In your own world: “*You don’t see girls with bald heads everywhere*”’ and ‘Finding a safe harbour’.

2.3.3.1 'Out of the loop'

A striking theme seen within many of the young people's stories was in relation to feeling somewhat disconnected from their friends. Abigail highlights this when she considers her relationship with her peers:

"I was kind of like forcibly, like it was out of their control and it was out of mine, but I was kind of taken out of the loop by not being at school...I'd lost a lot of friends"

(Abigail, 537-540)

Reflecting on why this disconnect may have occurred, Abigail explained how she would often sense apprehension in her peers, which she believed was a result of people *"not knowing what to say"*. This was supported by Joe who spoke about how certain people in his social circle didn't *"know how to talk about it"*, resulting in him feeling disconnected and less confident:

"You just think like, it knocks you down a little bit, because you think like, how can I explain, I'm still me, but they can't see that"

(Joe, 717-719)

Conversely, Jack and Adam spoke about how they chose to distance themselves from their friends whilst in hospital. For Jack, this position came from him not wanting other people to see him when he was so unwell, while Adam did not want people to act differently or *"make a big deal out of it"*:

"Probably just did not want them to see me constantly sick or in that position... I don't know...that's just me"

(Jack, 607-608)

In contrast, Claire spoke about how for her maintaining friendships were important. Highlighting the desire most young people shared, Claire reflects how being treated the same whilst undergoing treatment is vital, demonstrated here by her reflections of other people she had meet through treatment:

“...they don't speak to their friends anymore, and they treat them differently like they're ill. My friends don't, they still roll on the floor and do stupid stuff”

(Claire, 438-440)

2.3.3.2 'In your own world: *“You don't see girls with bald heads everywhere”*'

This theme voices the participants reflections of how being diagnosed with cancer propelled them into *“another world”*. Alesha revealed how for her, the hospital environment felt like *“quarantine”*, exposing her to situations she could never have imagined:

“Yeah you feel like you have been put in quarantine and that everyone... because you don't see all of them outside...you don't see girls with bald heads everywhere...so you feel like you're in you're own world”

(Alesha, 331-334)

Claire also commented on the unique and at times *“shocking”* nature of the hospital environment, talking about how she would often see *“babies”*, and *“toddlers”* *“going through”* treatment. This upturned reality was also difficult for Jack, who described how he often struggled with seeing the effects of cancer treatment:

“being on the ward all of a sudden, you're seeing people walking by...missing arms or there was one girl who had her eye removed...it's like ...you don't see that sort of stuff...and to all of a sudden be put in there it's... it's hard to see”

(Jack, 956-960)

In addition to discovering this new world, being exposed to other people with cancer was something that Joe found difficult. Reflecting on how seeing others go through treatment, was a stark reminder of what might happen to him:

“I was seeing other people and I was thinking I'm going to be like that, because I've got cancer, but then after a bit I just started to think about it a bit more and a bit more, and each loss, it started to affect me more”

(Joe, 1085-1088)

2.3.3.3 'Finding a safe harbour'

Given the diverse and at times chaotic nature of cancer treatment, many of the participants spoke to the need for a place of solace and safety. For Adam, this was in the form of medical staff, putting his faith in the team around him, *“they know what they're doing so just go with whatever they are saying”*. This was echoed by Joe who took comfort from the fact he was *“in the best hands”* and receiving the *“best treatment”* available.

Despite certain challenges, the ward also epitomised a place of safety for some young people. Alesha reflected that despite it feeling like *“quarantine”*, staff tried to

make her stay as comfortable as possible which was helped by a range of facilities and activities which made her feel more at “home”:

“you have TVs, X Box, you have music...there was a music teacher that comes and teaches you keyboard, guitars, if you want to sing you sing...it kind of brings you...makes you feel like home...”

(Alesha, 364-368)

Such mixed feelings were also felt by Jack, who despite finding the hospital environment challenging, sought comfort from nurses and support staff. Jack also commented on the new relationships he had formed with other cancer patients, speaking about how it was easier to relate to one another as they were “*in the same boat*”. Such unity was something shared amongst most of the participants and is articulated here by Jack’s experience:

“there was one night in particular where it was like a camp fire... we were all up ...all the lads there was four in one bay everyone was or talking laughing that was, that was a great night”

(Jack, 1236-1239)

Not all young people found comfort from staff or other young people with cancer, instead turning to their family and friends. Claire described how she did meet other young people, but did not “*make strong connections*”, instead describing how she was happy with her support network and wanted to “*stick to them*”. For Abigail and Adam, the biggest sense of support came from their family, reflecting on how their

experiences lead to them “*spending more time*” with loved ones, characterised here by Abigail’s reflection on the relationship with her mom:

“I think, I am a lot closer to my mom which is like a positive, because I have spent so much time with her in hospital, err, we definitely, like we get each other a lot more because we have been almost, we have had to be together because I don’t want to be on my own”

(Abigail, 555-559)

2.4. Discussion

2.4.1 Discussion of findings

This study brought light to the lived experiences of a diverse range of young people (aged 13-24) with cancer. Three superordinate themes emerged from the data displaying the complex and often demanding picture of what it is like to live with cancer as a young person in the UK. From comprehending a life with cancer, to coping with the adversarial nature of treatment, participants navigate a host of trials and tribulations, questioning their identity and the world in which they have been propelled into. Demonstrating resilience and resolve young people reflected on how such experiences had contributed to a new sense of purpose and meaning, all of which was driven by a determination to survive and overcome their condition.

2.4.1.1 A natural injustice

An assortment of lived truths corroborated the varied and yet harmonious experiences of living with and undergoing treatment for cancer as a young person. This included grappling with a new-found reality and a coming to terms with a new characteristic which at times felt like it embodied who they were. This research supported findings found amongst the adult population, with a number of young people participating in self-recrimination in order to make sense of their diagnosis (Block, Dafter, & Greenwald, 2006).

Many of the young people involved within the project reflected on the strenuous and often incarcerating nature of cancer treatment, raising questions about how young people are prepared for treatment. As such, mental health input as recommended by

the NICE guidelines (NICE, 2014) may be able to facilitate conversations that encapsulate the intense nature of treatment and mediate any concerns and apprehensions.

2.4.1.2 Get ready for battle: Cancer as an adversary to youth

Findings here demonstrated the often belligerent and adversarial nature of treatment, together with the resilient and optimistic approach young people adopted in order to manage and retain their identity. Cancer appeared to be an antagonist to youth, and at times this raging and powerful force seemed intent on disrupting such a vital and tentative developmental stage. Living with cancer as a young person propelled this cohort into a world far beyond their years, with young people having to negotiate and manage a range of emotions and important life decisions. Furthermore, many participants spoke about the loss of their new-found independence as a result of treatment, becoming more reliant on family members for support. This retreat to dependency supports the findings of Grinyer (2007) and Lewis et al. (2013), who found young people's development was often arrested by their cancer experience.

Evident throughout the narratives of those involved was a sense of being separate to their cancer. Many young people spoke about how it was their body that was failing rather than their mind, taking a more omnipotent position in order to focus their attention on recovery. A positive and optimistic outlook seemed pertinent to this cohort, who felt focusing on negative aspects of their condition may somehow hinder the recuperation of their healthy self. Despite early research suggesting patients demonstrating a "fighting spirit" were more likely to be disease free five to ten years post assessment (Greer, Morris, & Pettingale, 1979), multiple methodological limitations including small sample sizes and lack of statistical control for node status

means such claims have been refuted. Furthermore, with findings from a systematic review conducted by Petticrew, Bell, and Hunter (2002) revealing little evidence that optimism or “positive psychology” effects cancer progression and survival, the validity of such a widespread notion has to be questioned. Research has shown that patients can be overwhelmed with guilt or worry when being unable to remain positive, and as such health professionals must be aware and allow room for more complex or “negative” emotions (Dafer & Greenwald, 2006; Coyne & Tennen, 2010).

Finally, many of the young people expressed a more open minded and mature perspective as a result of their experiences, focusing more on living life and making memories. This was consistent with findings from previous research who found that young people can often have a changed outlook on life following a diagnosis of cancer (Lewis et al., 2013). Moreover, findings from a recent systematic review have highlighted how such reappraisals of life have the capability of generating greater self-development and transformation potential, akin to illness related Post Traumatic Growth (Hefferon, Greal, & Mutrie, 2009). However, not all appraisals were seen as progressive, with some members of the sample speaking to the “*loss*” of their younger years, suggesting a somewhat acrimonious response to having to deal with such responsibility at this youthful age.

2.4.1.3 The upside down: A parallel universe

A felt sense of being separate to the general population, together with exposure to a new and often frightening world can lead to young people feeling disconnected from the world around them. The present study supports findings from previous research

by Grinyer (2007) which depicts several key areas of young people's lives being affected as a result of their diagnosis. Friendship groups for some participants were stretched, with the young people often feeling "out of the loop". With findings from children's charity CLIC Sargent revealing 70% of young people experiencing depression at some point in their cancer journey, more needs to be done to help promote the importance of peer support and young people's wellbeing (CLIC Sargent, 2017). Furthermore, recent campaigns such as Macmillan's 'life with cancer is still life' could be expanded to include members of this population and help combat reflections like "*I'm still me, but they can't see that*" as shared by Joe.

Being thrust into hospital environments exposed the young people in our sample to the harsh reality of cancer treatment. Many participants reflected on the sights they witnessed whilst in hospital, adding how unusual and at times "*hard*" this was. With this in mind it is perhaps unsurprising that studies have reported incidences of cancer-related Post Traumatic Stress Disorder/Symptoms (PTSD/PTSS) ranging from 4.7% (Kazak et al., 2004) to 21% (Butler, Rizzi, & Handwerger, 1996) in childhood cancer survivors (Bruce, 2006). Despite guidelines stipulating the importance of emotional and psychological support for cancer patients, the focus for many of the young people was on treatment and physical recovery. Staff and support services, whilst needing to prioritise young people's physical health, should not neglect their emotional world. Simple meetings that help young people prepare for their own treatment, as well as what they may witness whilst in hospital may help reduce the prominent levels (90%) of anxiety reported by young people in a recent study (CLIC Sargent, 2017).

Despite these experiences, young people found solace in the hospital environment, together with their family and friends. Thus, suggesting that for the large part recommendations made in “A blueprint of care for teenagers and young adults with cancer” remain helpful, especially in relation to the ward environment and holistic care approach (Smith et al., 2012)

2.4.2 Methodological limitations

With a limited sample size, results cannot be transferred to all young people (13-24) with cancer. However, the convergence across the participants narratives together with the richness of detail provided, offers validity to these shared experiences. Furthermore, the potential limitations associated with one participant having finished treatment before the interview took place, have been considered with their narrative still providing a rich and authentic account of their cancer journey.

Finally, the difficulties associated with accessing this vulnerable population have been explored. Lengthy treatment regimens and associated side effects, together with the separation of services depending on age may have accounted for non-participation for some young people.

2.4.3 Clinical and service implications

The invidious position of being a young person with cancer, stresses the need for attuned and aligned clinical relationships. Furthermore, the environments in which young people are treated need to be a place of safety and acceptance, allowing for open discussions that speak to the emotional impact a diagnosis of cancer can have.

Services need to continue to support young people in a holistic manner, catering to the needs of individuals rather than the collective. Given the themes associated with self- recrimination and the need to remain “positive”, clinicians must juggle the delicate and multifaceted task of providing a sense of hope and promoting young people’s strength and determination, whilst also allowing for more difficult conversations. Given the potential difficulties in starting such discussions, psychology could support medical staff by providing training, facilitating reflective practice groups and offering supervision in order to help promote staff development.

Despite similarities relating to their cancer experience, age of diagnosis was linked to different experiences. The younger members of this cohort seemed to focus more on peer relationships and the effects cancer has had on their development. Whilst relating to these experiences, older participants also spoke to challenges in personal and romantic relationships, and as such clinicians must steer clear of a one size fits all approach, making adjustments depending on individual need. Thus, assessment and formulation encompassing individual’s experiences along with parental involvement is crucial in ensuring an holistic and distinct care package.

2.4.4 Recommendations for future research

Divergence amongst the young people’s accounts was mainly associated with participants’ age. With such a broad range (13-24), future research should attempt to explore experiences amongst different ages within this cohort.

Given this was the first IPA study with this population, social factors were not considered when recruiting participants. Future research could target a range of

participants who hold supplementary intersects of reduced privilege such as minority ethnic groups or those with comorbid or complex needs. Furthermore, gender specific experiences could be explored, to help provide more detailed accounts of experience.

With findings from a recent mixed methods study revealing elevated levels of anxiety and depression amongst young people with cancer, a more in depth qualitative enquiry focused on exploring potential precipitating factors may also be useful (CLIC Sargent, 2017).

2.5 Conclusion

This comprehensive qualitative enquiry has contributed to the limited literature concerning young people's experiences of cancer. Supporting findings from other qualitative studies, young people reported a diverse range of experiences which at times hindered their development. Navigating the world of cancer diagnoses and treatment is often fraught with challenges, however stories of resilience and determination are scattered throughout these young people's narratives.

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Chapter 3
Reflective Paper

**Reciprocity and Mutuality: A personal account of my research
experience.**

Chapter word count (excluding references): 3175

3.1. Introduction

A fundamental part of clinical psychology training, reflexivity and reflective practice, has propagated professional practice in recent years. Despite such unprecedented growth, the delineation of reflection can differ extensively, not only across, but within the same professions (Finlay, 2008). Notwithstanding a lack of consensus (Eraut, 2004; Finlay, 2008), I look at reflection as the opportunity to examine the influence that I can have upon my work, both as a clinician and as a researcher. With several learning models (Kolb, 1984; Johns, 1995; Gibbs, 1998) positioning self-reflection as the antecedent to change and growth, this chapter aims to provide a cogitated account of the reciprocal relationship between myself and my research. I will incorporate experiences of the entire research process, from conception to completion, and explore the effects this activity has had on my life at present and undoubtedly will have in the future. This process of reflection has been guided by a research journal and reflective diary written over the course of my training, and where relevant I have incorporated therapeutic models to help provide shape and clarity to my account.

3.2. Why Health?

“Exploring people’s experiences of adversity” and “Investigating Resilience and Spirit”, were just two quotes noted in my first-year reflective diary when thinking about what I would like to research. Although these statements could be just as fitting for exploring people’s experiences of a variety of hardships, my own personal life guided me to a more health related topic. My maternal grandfather was diagnosed with Huntington’s Disease (HD) in 2014, and my maternal grandmother had just “got the all clear” from ovarian cancer when I joined the course. These

experiences propelled me to a world of medical appointments, clinics, and encounters I had previously not recognised or understood, exposing me to how fragile and yet durable we are as humans. It was this collocation that acted as the starting point for my research journey, the start of a desire to want to explore and then express people's stories relating to their own health experiences. This, coupled with my passion and love for working with young people, inspired me to embark on the topics enlisted within this thesis.

3.3. Things change

"Grief does not change you, Hazel. It reveals you"

John Green, The Fault in Our Stars

As referenced above, when embarking on this research journey, both my maternal grandfather and grandmother had their own experiences of severe health problems. However, what seemed to be under control started to quickly unravel during my time on the course.

In January 2017, my family and I suffered the loss of my Nan. Despite encountering death of loved ones prior to this, I can honestly say that this was the hardest and most difficult I have yet to encounter. I had many questions and very few answers, and given the stage of my research, I felt confused and unsure about my progress with this subject matter. In October of the same year, my grandfather's symptoms of Huntington's Disease started to progress, resulting in him moving into supported living accommodation and leaving the house he had loved since I was young. These experiences again made me think about my research choices, and despite not

knowing what the future had in store, I could not help but question why I chose these topics.

I had previously reasoned that my choice of project resonated from a desire to better understand the experiences of those suffering from ill health. Furthermore, I believed it was important to study a topic in which I was interested and had a passion for, given research had never been the primary motivator for my career in psychology. However, on reflection in addition to the reasons listed above I feel my choice of topic may have fulfilled another role, one that helped me feel more connected with the experiences of my family. Since gaining a place on this course, I had left my home town which, coupled with increased academic pressures, led me to feel increasingly detached from my family. I know that despite doing the most I could, and being there for my family during these incidents, I was still left with a sense of guilt and sadness. This made me think about the triangle of conflict, and how defences are often employed to manage anxiety resulting from an underlying feeling (Malan, 1995). I started to think about how the guilt I held because of being more absent from my family, may have been sublimated into my choice of research in order to feel more connected (Lemma, 2003). Sublimation represents a process by which we invest our energy associated with difficult feelings or impulses into a task or activity. As such, it may be that my guilt and sadness about feeling disconnected from my family was diverted into the more prosocial or proactive behaviour of conducting my research.

Reflecting on these experiences, emphasises the importance of family and self-care. The literature relating to self-care amongst psychologists highlights a potential

deficit in this area, despite it being a crucial part of becoming an effective clinician (Figley, 2002; Norcross, 2002). Throughout my training, I have been heavily influenced by models of compassion and dynamic therapies that focus on the importance of emotional regulation and self-care (Coughlin & Katzman, 2013; Gilbert, 2010). Despite this, I often struggled to look at my own emotional world, and as such had difficulty in applying some of the very principles I recommend to my patients. Taking the time to consider these experiences has been incredibly useful. I noticed a direct shift in my behaviour in the weeks leading up to submission, offering myself gentle invitations to check in, as well as give myself permission to take breaks and reconnect with my loved ones. I found this process had a beneficial impact on my wellbeing, but also my work, both in relation to my project and clinical responsibilities.

3.4. In, Out and In-between

The qualitative researcher's perspective is perhaps a paradoxical one: it is to be acutely tuned-in to the experiences and meaning systems of others—to indwell—and at the same time to be aware of how one's own biases and preconceptions may be influencing what one is trying to understand.

Maykut and Morehouse, 1994, p. 123

Although free from cancer, my close relationship with the disease and its effects on my family, together with my new found “at risk” status in relation to HD, places me closer to the phenomenon under investigation. There is an array of literature exploring membership roles in qualitative research, with theories relating to both insider and outsider positions being debated over time (Dwyer & Buckle, 2009; Milligan, 2016).

An “insider” position relates to a researcher who has personal experience and belongs to the same cohort as their participants, while an “outsider” sits outside said group and has no prior union to the research population or field (Gair, 2012).

Alongside these positions lie inherent questions and contests, often relating to objectivity and bias. Adler and Adler (1987) delineate “complete member researchers” or ‘insiders’ may struggle with role conflict and confusion, being at risk of responding to the participants and or their data from a perspective other than that of a researcher. On the other hand, having exposure to the phenomenon you are studying affords a unique position of understanding and identification that may be missed by those with no prior experience (Dwyer & Buckle, 2009).

For me, the process of qualitative research itself cannot be objective. As a qualitative researcher, I am not separate from my research, but rather firmly positioned in the middle of it. One could argue regardless of personal exposure, we carry the stories of our participants around with us, letting them in to our world for us to make sense of them. In a sense, our personhood affects the research as much as the research affects our personhood. To try and create a “balance” by where my experiences could be valuable but not overbearing, I utilised “bracketing interviews” and my research journal to help identify and explore my own preconceptions and ensure they did not dominate my analysis. Bracketing can refer to a reflexive exercise whereby the researcher endeavours to recognise potential areas of conflict or bias within themselves, in order to ‘bracket’ (not ignore) them so as to reduce their influence upon the data (Ahern, 1999). For me, there were multiple preconceptions about what it would be like to be diagnosed with cancer, born from my own experiences, and those I had gathered via the media. I had anticipated that in addition to devastation

and distress, a sense of resilience would emerge. Furthermore, I had wondered about how these young people would make sense of their situation, and whether it would involve a certain amount of self-recrimination or attribution to external forces as seen in the adult population (Block, Dafer, & Greenwald, 2006). It was apparent when thinking about my own position, I could anticipate a certain degree of attribution to previously-ill-advised behaviour, whether that be linked or not. It was imperative that I obtained an awareness of these ideas and beliefs, so that I could be free to listen to the stories of my participants without imposing my own impressions and theories onto them. In this instance, themes of attribution and resilience were inherent in the data set. However, by acknowledging my own thoughts and ideas, I was able to help ensure this was a true reflection of the sample and not myself. It was by engaging in these reflexive processes that I came across a third position, the notion of the “space in-between” (Dwyer & Buckle, 2009). This was a space that opposed the dichotomy of insider versus outsider status and instead celebrated the dialectical nature of qualitative research (Dwyer & Buckle, 2009). It recognises that in spite of whether we fall closer to the insider position or not, our perspective just like our participants’ is unique and shaped by our own individual experiences.

3.5. Ethics and Recruitment

Given the topic under investigation, I was acutely aware of the need for sound ethical and moral considerations. However, I did not anticipate the extent to which this process challenged my thoughts about my ability and capacity to complete this project.

I originally started the process of obtaining ethical approval for this research in

January 2017, with approval from all relevant departments not being granted until September 2017. Over the course of those eight months, I attended multiple meetings, panels and service user feedback groups to try and ensure the most robust and ethically sound project possible. As this research involved participants within the NHS, it required ethical approval from my sponsoring organisation (Coventry University), The Health Research Authority (HRA) as well as permissions from both research and development departments at the local specialist cancer sites. Thinking about this process and in looking through my reflective journal, I remember a sense of feeling frustrated and trapped by both the length and restrictive nature of this activity. I found that it was difficult to satisfy all the parties involved, with conflicting information being provided at different points throughout the process. Furthermore, the perceived extent of worry and apprehension surrounding the project was surprising, and at times discouraging. I started to question my ability as a researcher, and in turn noticed an increase in my own anxiety about potentially working with this population. I utilised supervision to help explore these feelings, and address concerns I had about the feasibility of the project given these challenges. I found it was useful to reflect on the importance of ethical principles and how rather than interpreting feedback as a negative appraisal on my ability, to see it as a vital tool to help prevent negligence or harm. Furthermore, it was through this process that I was further able to accept that in my desire to want to tell the stories of this underrepresented sample, I may have overlooked certain elements required to ensure the project was safe not only for the young people involved, but also myself as a researcher. Working in this area has been emotionally demanding at times, and I do feel that this is something that I may have overlooked when planning this project. Obtaining support from both my academic and clinical supervisors during this

journey has been paramount to its success and my ability to keep moving forward.

In addition to the challenges associated with ethics, recruitment for this study was also very difficult. I started the recruitment process in September 2017, and by the end of February 2018, had only interviewed four people, all of which were over the age of 18. At this point I was extremely anxious that I would not be able to recruit a sufficient number of young people into the study and that I would not secure representation for the lower half of the age range (13-24). The process of recruitment was heavily reliant on the staff from the two local specialist cancer services, and whilst all the staff were extremely helpful and supportive, I was at times curious about the potential parallel processes at play.

Both Searles (1955) and Hora (1957) describe parallel processes as potential unconscious identifications with a client and their needs. During my time with staff I was often curious as to whether those involved in the care of young people who fell within the lower end of my sample (13-16) were more apprehensive about the project. I noticed their involvement at times was more distant, often contacting me via email rather than by phone or arranging meetings. Furthermore, when speaking to certain members of the team their approach was in certain instances indifferent, especially compared to clinical staff tasked with caring for young people aged 16-24. Through the use of clinical supervision, and retrospectively now that the data collection is over, I can also resonate with this potential divergence. Looking back at the interview process, I did notice slight differences in my initial feelings when talking to the two younger members of the sample. By the end of our time together, any initial hesitation had subsided, but this experience did leave me wondering if

there was a greater pull to protect or shield the younger participants. Since speaking to staff and indeed using my own reflections, I do feel more work in exploring our own feelings and perceptions of those we care for is needed. Furthermore, although it is imperative that we protect any participant from harm, especially those that are younger, by engaging them in research we are in a sense dignifying them and their experiences. Despite these challenges, I have learnt more about the importance of perseverance and determination when recruiting and researching hard to reach or vulnerable populations. As such, when thinking about future research, it would be wise to factor in the potential delays inherent with multiple ethical applications and a more obscure sample, especially given the multiple demands and clinical responsibilities inherent within a qualified position.

3.6 I was not expecting that: being a researcher, a clinician and a human

On returning to work after the Christmas break, I opened an email from a member of staff at one of the local specialist cancer services, informing me that one of the participants in my study had sadly died. As detailed above, my beliefs and position as a qualitative researcher means I attempt to embody the stories of those I am working with, letting them penetrate my life in order to try and understand their meaning. I did not see the meeting with this young person as just an “interview” but rather an “encounter” whereby I had the opportunity to see inside their world for a brief time.

I was left with a profound sense of sadness at this news, especially given the fragile and, at times, despairing narrative of the young person in question. I also had many questions, particularly in relation to their data and potential inclusion in the project. To help ensure I followed procedure I sought guidance from the HRA, which

stipulated that given the young person in question contested to the project prior to their death and was capacitous at the time, their account could be used. Furthermore, reflecting on our conversations prior to the interview, the young person talked about their desire to take part in this project, expressing how they wanted to contribute to something that could help other young people or the services that help them. With this in mind, I felt more comfortable in using their account, however was concerned about ensuring I do justice to their and the other young people's stories. Reflecting on the presence of these feelings enabled me to channel them into my work, helping ensure I spoke to the authentic and rich narratives I had been privileged to hear.

Utilising supervision to help recognise certain pulls, has helped me realise the need for a balance between subjectivity and objectivity as a researcher. As a human and clinician, I wanted to continue my involvement and contact the young person's family to express my condolences. However, it was by recognising that my objectivity as a researcher may have been a reason why they were able to speak to such length about their experience that assisted me to take a more cogitated approach. By identifying the friction that lay between my role as a researcher and clinician, I was able to reflect on the potential harm I may do by speaking to his family, especially as I did not have ethical approval or their consent to do so.

3.7 Conclusion

The research detailed within this thesis not only represents an academic requirement, but a personal voyage of both myself and the young people involved. I first started to contemplate research ideas in my first year of training, almost two years ago.

Looking back, the change and growth in myself as a clinician and researcher is

undeniable. I have spoken about how this research was born and how over time it has impacted me on both a personal and professional level. This project has shown me the importance of perseverance, especially in relation to recruitment and ethics, but has also highlighted how I position myself in relation to research and the importance of a balanced approach.

Exploring the link between researcher and research together with “In” and “Out” positions has lead me to believe the two are not separate entities but instead exist in parallel. Writing this thesis and reflecting on my experiences of this course more generally, has substantiated the importance of reflection on good and ethical practice, and is something that I will take forward in my life.

Further to this, embarking on this process has lead me to think more about my own personal identity especially in relation to my sample. My sense of privilege as a “healthy” young white male, has afforded me multiple opportunities in life, and rather than feeling guilty about these, I need to utilise them in order to help others who may be in a less fortunate position.

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Appendix A

Author guidelines for the Journal of Genetic Counseling

General guidelines for preparation and submission

General

Manuscripts should be checked for content and style (American English spelling, punctuation, and grammar; accuracy and consistency in the citation of figures, tables, and references; stylistic uniformity of entries in the References section; etc.)

Comments section: Authors should detail in the comments section of the submission that the manuscript is submitted solely to this journal and was not published elsewhere, and disclose details of any previous or anticipated publication history related to the manuscript's content. Submission is a representation that the manuscript has not been published previously and is not currently under consideration for publication elsewhere.

Manuscript Preparation

1. Type double-spaced and include all illustrations and tables. Original research articles should be no longer than 25 double-spaced typed pages and qualitative research no longer than 40 double-spaced typed pages.
2. Title page: A title page is to be provided and should include the title of the article, authors name (no degrees), authors affiliation, and suggested running head. The affiliation should comprise the department, institution (usually university or company), city, and state (or nation) and should be typed as a numbered footnote to the author's name. The suggested running head should be less than 80 characters (including spaces) and should comprise the article title or an abbreviated version thereof. The title page should also include the complete mailing address, telephone number, fax number, and e-mail address of the one author designated to review proofs.
3. Abstract: An unstructured abstract is to be provided, approximately 200 words
4. Key words: A list of 3-10 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.
5. Section headings: All major sections should carry section headings (such as Introduction, Methods, Results, Discussion, Conclusions, etc.) type centered. Side headings in Methods section should include, as appropriate: Participants, Instrumentation, Procedures, and Data Analysis. Side headings in Discussion should include: Study Limitations, Practice Implications, and Research Recommendations. All Acknowledgements (including those for grant and financial support) should be typed in one paragraph (so-headed) on a separate page that directly precedes the References section.
6. Reference list: The journal follows the reference and citation style recommendations of the Publication Manual of the American Psychological Association (APA style). See also: <http://apastyle.apa.org/>

List references alphabetically at the end of the paper. References should include (in this order): last name and initials of authors, year published, title of article, name of publication, volume number, and inclusive pages. Where there are seven or more authors, abbreviate the seventh and subsequent authors as et al.

Refer to the references in the text by name and year in parentheses. Multiple citations should be listed alphabetically by author's last name.

7. Illustrations: Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals. The captions for illustrations should be provided. Photographs and drawings should show high contrast. Electronic should be in TIFF or EPS format (1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CMYK color space. A hard copy of photographs or illustrations may be requested prior to publication.

8. Tables: Tables should be numbered (with Roman numerals) and referred to by number in the text. Each table should be on a separate sheet of paper at the end of the submission. Center the title above the table, and type explanatory footnotes (indicated by superscript lowercase letters) below the table.

9. Footnotes: Footnotes should be avoided. When their use is absolutely necessary, footnotes should be numbered consecutively using Arabic numerals and should be typed at the bottom of the page to which they refer. Place a line above the footnote, so it is set off from the text. Use the appropriate superscript numeral for citation in the text.

10. Pedigrees: Pedigrees should follow the recommendations for standardized nomenclature accepted by the National Society of Genetic Counselors. Authors should consult the following references for these recommendations:

Bennett, R. L. , Steinhaus, K. A., Uhrich, S. B., O' Sullivan, C. K., Resta, R. G. , Lochner-Doyle, D., Markel, D. S., Vincent, V., & Hamanishi, J. (1995). Recommendations for Standardized Human Pedigree Nomenclature. *Journal of Genetic Counseling*, 4, 267-279.

Bennett, R. L., Steinhaus French, K., Resta, R. G., & Lochner Doyle, D. (2008). Standardized Human Pedigree Nomenclature: Update and Assessment of the Recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counseling*, 17, 424-433.

11. Conflict of Interest: Conflict of interest statements should be present on every manuscript before the References section. The statement should mention each author separately by name. Recommended wording is as follows:

Author X declares that he has no conflict of interest.

Author Y has received research grants from Drug Company A.

Author Z has received a speaker honorarium from Drug Company B and owns stock in Drug Company C.

If multiple authors declare no conflict, this can be done in one sentence:

Author X, Author Y and Author Z declare that they have no conflict of interest.

12. Human Studies and Informed Consent: For studies with human subjects, please include the following statement before the References section:

'All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.'

If any identifying information about patients is included in the article, the following sentence should also be included:

'Additional informed consent was obtained from all patients for which identifying information is included in this article.'

13. Animal Studies: For studies with animals, include the following sentence in the manuscript before the References section:

'All institutional and national guidelines for the care and use of laboratory animals were followed.'

If the authors did not carry out animal studies as part of their article they must include the following statement in the manuscript before the References section:

'No animal studies were carried out by the authors for this article'

The editors reserve the right to reject manuscripts that do not comply with the above-mentioned requirements. The author will be held responsible for false statements or failure to fulfil the above-mentioned requirements.

Appendix B

Coventry University ethics approval for Chapter One Systematic Review

Certificate of Ethical Approval



Applicant:

Joshua Spooner

Project Title:

Experiences of predictive genetic testing for Huntington's disease: A meta-synthesis of the qualitative research

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

24 August 2017

Project Reference Number:

P60673

Appendix C

Adapted CASP instrument

Assessment of study quality – Adapted CASP form

Reviewer: _____ Date: _____

Author: _____ Year: _____ Record Number: _____

Assessment questions	Response (circle)		
1. Was there a clear statement of the research question(s) and/or the aim(s) of the research?	Yes	No	Unclear
2. Was a qualitative approach appropriate?	Yes	No	Unclear
3. Were the research methodology and design appropriate for addressing the research question?	Yes	No	Unclear
4. Was the sampling/recruitment strategy appropriate for addressing the research question?	Yes	No	Unclear
5. Were the methods of data collection appropriate for addressing the research question?	Yes	No	Unclear
6. Were the data analysis methods sufficiently rigorous and appropriate for addressing the research question?	Yes	No	Unclear
7. Is there a statement locating the researcher(s) culturally and/or theoretically?*	Yes	No	Unclear
8. Has the relationship between researcher and participants been adequately considered?*	Yes	No	Unclear
9. Are the participants and their voices adequately represented?*	Yes	No	Unclear
10. Have ethical issues been adequately taken into consideration, and is there evidence of ethical approval from an appropriate body?	Yes	No	Unclear
11. Is there a clear statement of findings?	Yes	No	Unclear
12. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?*	Yes	No	Unclear

*Item adapted from JBI-QARI qualitative critical appraisal instrument

Overall methodological rating (circle): **High** **Moderate** **Low**

Rationale and comments: _____

Appendix D

Inter-rater reliability coefficient (Kappa) scores

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.856	.057	9.859	.000
N of Valid Cases		72			

Overall Kappa score:

Kappa score for Andersson et al, 2013 paper:

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.657	.227	2.829	.005
N of Valid Cases		12			

Kappa score for Cox & McKellin, 1999 paper:

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.867	.128	4.083	.000
N of Valid Cases		12			

Kappa score for Gong et al, 2016 paper:

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.657	.227	2.829	.005
N of Valid Cases		12			

Kappa score for Sobel & Cowan, 2003 paper:

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.860	.134	4.072	.000
N of Valid Cases		12			

Kappa score for Taylor, 2004 paper:

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.867	.128	4.083	.000
N of Valid Cases		12			

Kappa score for Theed et al, 2017 paper:

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	4.846	.000
N of Valid Cases		12			

Appendix E

Meta-ethnographic method

The seven steps identified by Noblit and Hare (1988) as summarised by France et al. (201 pp 5)



Appendix F

Author guidelines for submission to the British journal of Health Psychology

Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview.

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which report analyses on established theories in health psychology;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses); and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words, or 6,000 words for qualitative papers)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found [here](#).
- Statement of Contribution: All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

- Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.
- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and always refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book*. City, Country: Publisher.
 Author, A. (2013). Title of journal article. *Name of journal*, 1, 1-16. doi:
 10.1111/bjep.12031

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.
- Manuscripts reporting systematic reviews and meta-analyses are encouraged to submit in accordance with the PRISMA statement.
- Manuscripts reporting interventions are encouraged to describe them in accordance with the TIDieR checklist.

If you need more information about submitting your manuscript for publication, please email Hannah Wakley, Managing Editor (bjhp@wiley.com) or phone +44 (0) 116 252 9504.

6. Supporting information

We strongly encourage submission of protocol papers or trial registration documents, where these are in the public domain, to allow reviewers to assess deviations from these protocols. This will result in reviewers being unblinded to author identity.

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.

For further information on recommended file types and requirements for submission, please visit the Supporting Information page on Author Services.

7. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. A full list of terms and conditions is available on Wiley Online Library.

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form.

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

8. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. You can then access Kudos through Author Services, which will help you to increase the impact of your research. Visit Author Services for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

9. Copyright and licences

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where

via the Wiley Author Licensing Service (WALS) they will be able to complete the licence agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs .

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons Licence Open Access Agreements (OAA):

- Creative Commons Attribution Non-Commercial Licence (CC-BY-NC)
- Creative Commons Attribution Non-Commercial -NoDerivs Licence (CC-BY-NC-ND)

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs and you may also like to visit the Wiley Open Access Copyright and Licence page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY licence supporting you in complying with your Funder requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit our Funder Policy page.

10. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in Author Services. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from Adobe's web site. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof.

Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document. What happens to my paper? Appeals are handled according to the procedure recommended by COPE.

Appendix G

HRA guidance for the principles of consent for deceased participants

Principles of consent: Deceased people

Consent given prior to death, is believed to extend beyond death.

However, relatives may have a different opinion, once their relative has died. This should be handled sensitively with relatives being encouraged to respect the deceased person's wishes (or in certain cases, their nominated representative / nominee, see below).

In legal terms, the Data Protection Act no longer applies to identifiable data that relate to a person once they have died.

However any duty of confidence established prior to death does extend beyond death. It is important to maintain confidentiality to ensure that trust in services and institutions are not undermined. Disclosure of confidential information post mortem therefore requires consent to extend the duty of confidence.

If you intend to collect tissue from a deceased person, to use tissue removed from the deceased or to conduct a post mortem purely for research purposes consent is required across the UK.

Tissue removed as part of a Coroner's / Procurator Fiscal's post mortem can be used for research, once they are no longer required for such legal purposes, however consent for use in research must be in place.

Although legal details may vary between the nations within the UK, the same basic legal and ethical principles apply in terms of the consent required:

- The person themselves can give consent for their tissues to be used for research prior to their death. If the person was not able to consent for themselves prior to death (due to lack of capacity), someone else may have been asked to provide consent, assent or advice on their behalf (visit '[Principles > Adults who are not able to consent for themselves](#)').
- Consent given before death should be respected, even when relatives may initially disagree.
- If consent is not in place, and the person has not specifically refused prior to their death:
 - In **England, Wales and Northern Ireland** an adult can nominate someone to represent them after their death and to give consent on their behalf. The nominated representative's consent cannot be overridden by other individuals, including those in a [qualifying relationship](#).
 - In **Scotland** a person can be nominated by anyone (aged 12 or over) before their death, to represent them after death. A nominee can then give authorisation (equivalent to consent) on behalf of the deceased person.
- If consent has not been sought from the above, the following can provide legally appropriate consent (or 'authorisation' in Scotland) on behalf of the deceased person:
 - In **England, Wales and Northern Ireland**, those in a qualifying relationship.
 - In **Scotland**, [nearest relative](#).

Appendix H

Coventry University ethics approval for Chapter Two Empirical Paper



Certificate of Ethical Approval

Applicant:

Joshua Spooner

Project Title:

Young peoples lived experiences of cancer: An Interpretative
Phenomenological Analysis

This is to certify that the above named applicant has completed the
Coventry University Ethical Approval process and their project has been
confirmed and approved as High Risk

Date of approval:

11 May 2017

Project Reference Number:

P50456

Appendix I

National Health Service Ethics Committee approval letter ((REC reference; 17/WM/0235)



Health Research Authority

Mr Joshua Spooner
Coventry University, Priory Street

Email: hra.approval@nhs.uk

Coventry
CV1 5FB

03 August 2017

Dear Mr Spooner

Letter of HRA Approval

Study title:	Young people's lived experiences of cancer: An Interpretative Phenomenological Analysis
IRAS project ID:	222228
REC reference:	17/WM/0235
Sponsor	Coventry University

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities

- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

Page 1 of 8

and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.

- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **222228**. Please quote this on all correspondence.

Yours sincerely

Beverley Mashegede

Assessor

Email: hra.approval@nhs.net

Copy to: Prof Ian Marshall, Sponsor Contact
 Dr Chris Counsell, Lead NHS R&D Contact

List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	3	05 May 2017
Covering letter on headed paper [Cover Letter for REC]		20 July 2017
Covering letter on headed paper [Cover Letter for REC]	01/08/2017	01 August 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		11 May 2017
GP/consultant information sheets or letters [GP Notification Letter]	2	01 August 2017
Interview schedules or topic guides for participants [Interview Guide]	2	16 March 2017
IRAS Application Form [IRAS_Form_30052017]		30 May 2017
IRAS Application Form XML file [IRAS_Form_30052017]		30 May 2017
IRAS Checklist XML [Checklist_01082017]		01 August 2017
Letter from sponsor		11 May 2017
Non-validated questionnaire [Short Questionnaire]	1	18 July 2017
Other [Debrief Participant]	5	01 August 2017
Other [Liability Insurance from Sponsor]		11 May 2017
Other [Sponsor Ethics Approval Certificate]		11 May 2017
Other [Debrief Participant]	3	05 April 2017
Other [Debrief Parent/Guardian]	3	05 April 2017
Participant consent form [Informed Consent Parent/Legal Guardian]	5	01 August 2017
Participant consent form [Assent 16 and under]	5	01 August 2017
Participant consent form [Informed Consent 16 and Over]	5	01 August 2017
Participant information sheet (PIS) [Participant Information 16 and over]	5	01 August 2017
Participant information sheet (PIS) [Participant Information 16 and under]	5	01 August 2017
Participant information sheet (PIS) [Participant Information Parent/Guardian]	5	01 August 2017
Research protocol or project proposal [Research Proposal]	5	20 July 2017
Summary CV for Chief Investigator (CI)		23 May 2017
Summary CV for student		23 May 2017
Summary CV for supervisor (student research)		24 May 2017
Summary CV for supervisor (student research)		14 February 2012
Summary CV for supervisor (student research)		

Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Prof Ian Marshall

Tel: 02476795294

Email: i.marshall@coventry.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Sponsor intends to use the Statement of Activities as the form of agreement with participating organisations.

4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this
Section	HRA Assessment Criteria	Compliant with Standards	Comments
			research study.
4.3	Financial arrangements assessed	Yes	No application for external funding made. No funds will be provided to the participating organisations.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	Provisional Opinion issued 29 June 2017. Favourable Opinion with conditions met issued 03 August 2017.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a student study (Doctoral Thesis in Clinical Psychology) and there is one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Local Collaborator is expected at each participating organisation.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

For research team members undertaking activities that do not impact on the quality of care of the participant (listed in A18), a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix J

Semi-structured interview schedule



Interview guide

1. Can we start by you telling me a little bit about yourself?
2. What was life like just before your diagnosis?
3. What was life like just after you received your diagnosis?
4. How has life been similar and different since receiving your diagnosis and undergoing treatment?
5. How have your relationships with others been since your diagnosis?
6. What is the difference between you before diagnosis to you now?
7. How similar and or different are your thoughts about the future?
8. Is there anything else you feel is important to tell me?

Prompts:

Can you give me an example?

Can you expand on that a little?

How did you feel about that?

What did that feel like?

What thoughts were going through your head?

What affect did that have on you?

You mentioned.....can you tell me what that experience means to you?

How did you feel when that happened?

How did that impact on you?

Appendix K

Participant information sheet 16 and over



Participant Information Sheet for Participants 16 and over

Young peoples' lived experiences of cancer: An Interpretative Phenomenological Analysis

You are being invited to take part in an interview exploring your experiences of being diagnosed with cancer. This will form part of a research project being completed as part of the researcher's doctoral thesis which is required for the completion of the Clinical Psychology Doctorate program at the Universities of Coventry and Warwick. The lead researcher is Joshua Spooner, a Trainee Clinical Psychologist

Before you decide whether you would be interested in taking part, please read the following information about the project and what would be involved.

What is the purpose of this research?

Research looking at young peoples' lived experiences of cancer is limited. Other projects have largely focused on the physical and social needs of young people. This research however wants to focus on what life has been like for you during this difficult time.

Why have I been invited to take part in the research?

You have been invited to take part in this research because:

- You are aged between 13-24 years' old
- You are 6 -18 months post initial diagnosis
- You are currently undergoing treatment/are in partial remission

Do I have to take part?

No. Participation within this study is voluntary; meaning it is entirely up to you whether you take part or not. If you decide not to take part, this will have no impact on your treatment.

If you do wish to take part, you will be asked to sign a consent form confirming you have read and understood the information sheet and wish to proceed. You can decide to withdraw your data up to two weeks following the interview without giving any reason and again without any consequence. This is due to the likelihood of data being analysed after this time. To withdraw you just need to contact Josh using the contact details at the end of this sheet.

What will happen to me if I take part?

Taking part will involve the completion of a short questionnaire asking a little bit about you (your age, type of cancer etc.) and you will have the opportunity to discuss the research with Josh before deciding if you would like to sign the consent form and take part.

If you do want to go ahead, Josh will write to your GP informing them of your participation. He will then contact you to set up a time where you can talk about your experiences of being diagnosed with cancer. The discussion can be held anywhere that is most convenient for you so this could be at home or in a meeting room at your local treatment center (Birmingham Children's Hospital or the Queen Elizabeth Hospital) or at Coventry University.

The conversation will largely focus on your experience of being diagnosed with cancer as a Young Adult, so Josh will ask questions about what life was like before and after your diagnosis. Josh will raise some areas for discussion, however the main focus and interest is what you think has been significant since being diagnosed and as such will generally be led by you.

To ensure that all information is captured during the discussion, a digital recorder will be used to record the process. Once the interview has been transcribed the recordings will be destroyed. Transcripts will be anonymised meaning any information identifying you will be removed.

When Josh begins looking at the data he may wish to spend some time with you to go over the main themes from your discussion or to make sure he has understood what you meant. This is so he can make sure he has captured your individual experience accurately.

What are the possible advantages and disadvantages of taking part?

Sometimes it is hard to tell people exactly what life is like, especially when we are going through something that is difficult. By taking part, you will have the opportunity to talk about your own experiences of being diagnosed with cancer, from your perspective. Your participation will also hopefully go towards helping inform professionals and other young people what life can be like as a TYA with cancer.

However, talking about your experience and thinking about what life has been like can be difficult. As such, you can stop the interview at any point and can take as many breaks as you need. You will also be provided with information where you can access further support if required and can talk to Josh about being referred to a healthcare professional who can provide support.

What will happen with my information?

Any personal information provided throughout your participation will remain confidential. Data from the interview between you and Josh will be recorded, stored and then destroyed.

You will be assigned an alternative name and this will be used when using quotations or providing information from what you talked about. Your data will be stored securely on an encrypted storage device, password protected computer or in a locked cabinet. The audio recording from the interview will be destroyed once Josh has written it up.

All remaining anonymised data will be destroyed in accordance with the university's policy which currently is 5 years. When talking to Josh, if you mention yourself or anyone else who might be at-risk, either to themselves or from others, Josh may have to tell other professionals in order to keep you safe. However, this will always be discussed with you where possible

What will happen to the results of the research?

This project is being completed as part of Josh's doctoral thesis which is required for the completion of the Clinical Psychology Doctorate program at the Universities of Coventry and Warwick.

The results of the study may also be made available to a wider audience via meetings, workshops, conferences and/or publication in relevant academic journals but you will not be identified in any way.

Who has reviewed the study?

This project has been approved to be undertaken by the University of Coventry's Research Ethics Committee and the South Birmingham NHS Research Ethics Committee.

What if I am not happy about this research or there is a problem?

If you have any concerns or queries about the research, please contact the lead researcher Joshua Spooner, or the research supervisors Dr Carolyn Gordon or Jackie Knibbs (contact details listed below).

If you wish to make a complaint please contact the Associate Pro-Vice-Chancellor, Olivier Sparagano on olivier.sparagano@coventry.ac.uk

If I want to participate in the research, what will happen next?

If you would like to take part please contact Joshua Spooner (details below) who will get back to you to explain what happens next.

Contact details

If you have any questions following reading this information sheet, please do not hesitate to get in touch to discuss any concerns or questions.

Joshua Spooner, Lead Researcher and Trainee Clinical Psychologist. *E-mail:* spooner10@uni.coventry.ac.uk *Tel.* 024 7765 7806.

Dr Carolyn Gordon, or **Jackie Knibbs** Research Supervisor, Clinical Psychology

Doctorate, Health and Life Sciences, James Starley Building, Coventry University, Priory Street, Coventry, CV1 5FB *E-mail:* / *Tel.* 024 7765 7806.

Patient Advice and Liaison Service (PALS) at Queen Elizabeth Hospital Birmingham.

E-mail: PALS@uhb.nhs.uk

Tel: 0121 371 3280

Patient Advice and Liaison Service (PALS) at Birmingham Children's Hospital

E-mail: bwc.pals@nhs.net

Tel: 0121 333 8403/ 0121 333 8505

Appendix L

Participant information sheet 16 and under



Participant Information Sheet for Participants Under 16

Young peoples' lived experiences of cancer: An Interpretative Phenomenological Analysis

You are being invited to take part in an interview exploring your experiences of being diagnosed with cancer. This will form part of a research project being completed as part of the researcher's doctoral thesis which is required for the completion of the Clinical Psychology Doctorate program at the Universities of Coventry and Warwick. The lead researcher is Joshua Spooner, a Trainee Clinical Psychologist

Before you decide whether you would be interested in taking part, please read the following information about the project and what would be involved.

What is the purpose of this research?

Research looking at young peoples' lived experiences of cancer is limited. Other projects have largely focused on the physical and social needs of young people. This research however wants to focus on what life has been like for you during this difficult time.

Why have I been invited to take part in the research?

You have been invited to take part in this research because:

- You are aged between 13-24 years' old
- You are 6 -18 months post initial diagnosis
- You are currently undergoing treatment/are in partial remission

Do I have to take part?

No. Participation within this study is voluntary; meaning it is entirely up to you whether you take part or not. If you decide not to take part, this will have no impact on your treatment.

If you do wish to take part, you will be asked to sign an assent form and your parent/guardian will be asked to provide informed consent on your behalf. In order to participate both you and your parent/guardian must agree for you to take part.

You can decide to withdraw your data up to two weeks following the interview without giving any reason and again without any consequence. This is due to the likelihood of data being analysed after this time. To withdraw you just need to contact Josh using the contact details at the end of this sheet.

What will happen to me if I take part?

Taking part will involve the completion of a short questionnaire asking a little bit about you (your age, type of cancer etc.) and you will have the opportunity to discuss the research with Josh before deciding if you would like to sign the assent form and take part.

If you do want to go ahead, Josh will write to your GP informing them of your participation. He will then contact you to set up a time where you can talk about your experiences of being diagnosed with cancer. The amount of time this will take will vary, depending on how much you wish to share however it should last no longer than 60-70 minutes.

The discussion can be held anywhere that is most convenient for you and your parent/guardian, so this could be at home or in a meeting room at your local treatment center (Birmingham Children's Hospital or the Queen Elizabeth Hospital) or at Coventry University.

The conversation will largely focus on your experience of being diagnosed with cancer as a Teenager, so Josh will ask questions about what life was like before and after your diagnosis. Josh will raise some areas for discussion, however the main focus and interest is what you think has been significant since being diagnosed and as such will generally be led by you.

In order to ensure that all information is captured during the discussion, a digital recorder will be used to record the process. Once the interview has been transcribed (written up) the recordings will be destroyed. Transcripts will be anonymised meaning any information identifying you to you will be removed.

When Josh begins looking at the data he may wish to spend some time with you to go over the main themes from your discussion or to make sure he has understood what you meant. This is so he can make sure he has captured your individual experience accurately.

What are the possible advantages and disadvantages of taking part?

Sometimes it is hard to tell people exactly what life is like, especially when we are going through something that is difficult. By taking part, you will have the opportunity to talk about your own experiences of being diagnosed with cancer, from your perspective. Your participation will also hopefully go towards helping inform professionals and other young people what life can be like as a teenager with cancer.

However, talking about your experience and thinking about what life has been like can be difficult. As such, you can stop the interview at any point and can take as many breaks as you need. You will also be provided with information where you can access further support if required and can talk to Josh about being referred to a healthcare professional who can provide support.

What will happen with my information?

Any personal information provided throughout your participation will remain confidential. Data from the interview between you and Josh will be recorded, stored and then destroyed.

You will be assigned an alternative name and this will be used when using quotations or providing information from what you talked about. Your data will be stored securely on an encrypted storage device, password protected computer or in a locked cabinet. The audio recording from the interview will be destroyed once Josh has written it up.

All remaining anonymised data will be destroyed in accordance with the university's policy which currently is 5 years. When talking to Josh, if you mention yourself or anyone else who might be at-risk, either to themselves or from others, Josh may have to tell other professionals in order to keep you safe. However, this will always be discussed with you where possible

What will happen to the results of the research?

This project is being completed as part of Josh's doctoral thesis which is required for the completion of the Clinical Psychology Doctorate program at the Universities of Coventry and Warwick.

The results of the study may also be made available to a wider audience via meetings, workshops, conferences and/or publication in relevant academic journals but you will not be identified in any way.

Who has reviewed the study?

This project has been approved to be undertaken by the University of Coventry's Research Ethics Committee and the South Birmingham NHS Research Ethics Committee.

What if I am not happy about this research or there is a problem?

If you have any concerns or queries about the research, please contact the lead researcher Joshua Spooner, or the research supervisors Dr Carolyn Gordon or Jackie Knibbs (contact details listed below).

If you wish to make a complaint please contact the Associate Pro-Vice-Chancellor, Olivier Sparagano on olivier.sparagano@coventry.ac.uk

If I want to participate in the research, what will happen next?

If you would like to take part please contact Joshua Spooner (details below) who will get back to you to explain what happens next.

Contact details

If you have any questions following reading this information sheet, please do not hesitate to get in touch to discuss any concerns or questions.

Joshua Spooner, Lead Researcher and Trainee Clinical Psychologist. *E-mail:* spoone10@uni.coventry.ac.uk *Tel.* 024 7765 7806.

Dr Carolyn Gordon, or **Jackie Knibbs** Research Supervisor, Clinical Psychology
Doctorate, Health and Life Sciences, James Starley Building, Coventry University, Priory Street, Coventry, CV1 5FB *E-mail:* / *Tel.* 024 7765 7806.

Patient Advice and Liaison Service (PALS) at Queen Elizabeth Hospital
Birmingham.

E-mail: PALS@uhb.nhs.uk

Tel: 0121 371 3280

Patient Advice and Liaison Service (PALS) at Birmingham Children's
Hospital

E-mail: bwc.pals@nhs.net

*Tel: 0121 333 8403/ 0121
333 8505*

Appendix M

Parent/Legal guardian information sheet



Participant Information Sheet

Parents/Legal Guardian

Young peoples' lived experiences of cancer: An Interpretative Phenomenological Analysis

Your child is being invited to take part in an interview exploring their experiences of being diagnosed with cancer. This will form part of a research project being completed as part of the researcher's doctoral thesis which is required for the completion of the Clinical Psychology Doctorate program at the Universities of Coventry and Warwick. The lead researcher is Joshua Spooner, a Trainee Clinical Psychologist.

Before you decide whether you feel this is something your child would be interested in, please read the following information about the project and what would be involved.

What is the purpose of this research?

Previous research looking at young peoples' lived experiences of cancer is limited. Other projects have largely focused on the physical and social needs of young people. Whilst important, this project aims to conduct interviews that focus on what life is like for young people during this difficult time.

Why has my child been invited to take part in the research?

Your child has been invited to take part in this research because:

- They are aged between 13-24 years' old
- They are 6 -18 months post initial diagnosis
- They are currently undergoing treatment

Does my child/relative have to take part?

No. Participation within this study is voluntary; meaning it is entirely up to you and your child whether they take part. If you both decide not to take part, this will have no impact on their treatment or services, now or in the future.

If you both feel this is something you would like to be involved in, you will be asked to sign an informed consent form on behalf of your child and they will be required to sign a assent form. In order for them to participate both you and your child must agree to take part.

You and your child can decide to withdraw two weeks following your interview without giving any reason and again without any consequence. This is due to the likelihood of data being analysed after this time. To withdraw you just need to contact Josh using the contact details at the end of this sheet.

What will happen to my child if they take part?

Taking part will involve the completion of a short questionnaire asking a little bit about your child (your age, type of cancer etc.) and you will have the opportunity to discuss the research with Josh before deciding if you want your child to take part.

If you do wish to proceed, Josh will write to your child's GP informing them of their participation. He will then set up a time where your child can talk about their experiences of being diagnosed with cancer. The amount of time this will take will vary, depending on how much they wish to share however it should last no longer than 60-70 minutes.

The discussion can be held anywhere that is most convenient for you and your child so this could be at home or in a meeting room at your local treatment center (Birmingham Children's Hospital or the Queen Elizabeth Hospital) or at Coventry University.

The conversation will largely focus on their experience of being diagnosed with cancer as a Teenager or Young Adult (TYA) so Josh will ask questions about what life was like before and after their diagnosis. Josh will raise some areas for discussion, however the focus and interest is what the young person thinks has been significant since being diagnosed and as such will generally be led by them.

In order to ensure that all information is captured during the discussion, a digital recorder will be used to record the process. Once the interview has been transcribed the recordings will be destroyed. Transcripts will be anonymised meaning any information relating to your child will be removed.

When Josh begins looking at the data he may wish to spend some more time with your child to go over the main themes from the discussion or to make sure he has understood what they meant. This is so he can make sure he has captured their individual experience accurately.

What are the possible advantages and disadvantages of taking part?

Sometimes it is hard to tell people exactly what life is like, especially when we are going through something that is difficult. By taking part, your child will have the opportunity to talk about their own experiences of being diagnosed with cancer, from their perspective. Their participation will also hopefully go towards informing professionals of what life can be like as a TYA with cancer, as well as provide real accounts to other TYA in a similar position.

However, at times talking about our experiences and thinking about what life has been like can be difficult. As such, the young person can stop the interview at any point and can take as many breaks as they need. An information sheet will also be provided, listing a variety of services where you and your child can access further support if required. You can also talk to Josh about being referred to a healthcare professional that can provide further support.

What will happen with my child's information?

Any personal information provided throughout your child's participation will remain confidential. Data from the interview between them and Josh will be recorded and stored before being destroyed.

Your child will be assigned an alternative name and this will be used when using quotations or providing information from what we have talked about. All data will be stored securely on an encrypted storage device, password protected computer or in a locked cabinet. The audio recording from the interview will be destroyed once Josh has written it up. All remaining anonymised data will be destroyed in accordance with the university's policy which currently is 5 years.

When talking to Josh, if your child talks about themselves or anyone else who might be at-risk, either to themselves or from others, Josh may have to tell other professionals in order to keep you and your child safe. However, this will always be discussed with you where possible.

What will happen to the results of the research?

This research forms part a doctoral thesis which is required for the completion of the Clinical Psychology Doctorate program at the Universities of Coventry and Warwick. The results of the study may also be made available to a wider audience via meetings, workshops, conferences and/or publication in relevant academic journals but neither you nor your child will be identified in any way.

Who has reviewed the study?

This project has been approved to be undertaken by the University of Coventry's Research Ethics Committee and the South Birmingham NHS Research Ethics Committee.

What if I am not happy about this research or there is a problem? If you have any concerns or queries about the research, please contact the lead researcher Joshua Spooner, or the research supervisors Dr Carolyn Gordon or Jackie Knibbs (contact details listed below).

If you wish to make a complaint please contact the Associate Pro-Vice-Chancellor, Olivier Sparagano on olivier.sparagano@coventry.ac.uk

If I agree to my child/relative taking part in the research, what will happen next?

If you would like to take part, please contact Joshua Spooner (details below) who will get back to you to explain what happens next.

Contact details

If you have any questions following reading this information sheet, please do not hesitate to get in touch to discuss any concerns or questions.

Joshua Spooner, Lead Researcher and Trainee Clinical Psychologist. *E-mail:* spoone10@uni.coventry.ac.uk *Tel.* 024 7765 7806.

Dr Carolyn Gordon, or **Jackie Knibbs** Research Supervisor, Clinical Psychology Doctorate, Health and Life Sciences, James Starley Building, Coventry University, Priory Street, Coventry, CV1 5FB.
Tel. 024 7765 7806.

Patient Advice and Liaison Service (PALS) at Queen Elizabeth Hospital
Birmingham.

E-mail: PALS@uhb.nhs.uk

Tel: 0121 371 3280

Patient Advice and Liaison Service (PALS) at Birmingham Children's
Hospital

E-mail: bwc.pals@nhs.net

*Tel: 0121 333 8403/
0121 333 8505*

Appendix N

Participant informed consent form 16 and over



Participant Consent Form for Participants aged over 16

Title of Project: *Young peoples' lived experiences of cancer: An Interpretative Phenomenological Analysis*

Name of Participant:

Name of Investigator: Joshua Spooner

	Please Initial:
I confirm that I have read the information sheet dated (version.....) for the above study	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected	
I understand that relevant sections of my medical notes and data collected during the study, may be looked at by the research team or staff within the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	

I understand that the information that I provide during this study will be processed and analysed as is required and in accordance with the Data Protection Act. This includes an audio recording of the interview. I understand that this information will be anonymised, all indefinable information removed and digital recordings will be destroyed after they have been transcribed. After completing the project, anonymised transcripts will be held at the university and then destroyed in line with university policy	
I agree to anonymised quotes from my interview being quoted verbatim in reports and publications related to this study.	
I agree for my GP to be notified of my participation within this study	
I agree to participate in the above study	

As stated in the information sheet, it may be that once the lead researcher has been through the interview they wish to interview you again to clarify things noticed in the original interview. This is simply to ensure that they have a deeper understanding of your experience. **If a second interview is required and you wish to take part, please initial the following box:**

I DO wish to take part in a second interview if required	
---	--

I wish to see a copy of the results and I would like it emailed/posted to:

.....

Signature of Participant

Name

Date

Signature of researcher

Appendix O

Parent/Guardian Informed Consent form 16 and under



Informed Consent Form for Parents/Legal Guardian

Title of Project: *Young peoples' lived experiences of cancer: An Interpretative Phenomenological Analysis*

Name of Parent(s) or Guardian(s):

Name of child/relative:

Name of Investigator: Joshua Spooner

	Please Initial:
I confirm that I have read the information sheet dated (version.....) for the above study	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason and without their medical care or legal rights being affected	

I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by the research team or staff within the NHS Trust, where it is relevant to their taking part in this research. I give permission for these individuals to have access to my child's records.	
I understand that the information that my child provides during this study will be processed and analysed as is required and in accordance with the Data Protection Act. This includes an audio recording of the interview. I understand that this information will be anonymised, all indefinable information removed and digital recordings will be destroyed after they have been transcribed. After completing the project, anonymised transcripts will be held at the university and then destroyed in line with university policy	
I agree to anonymised quotes from my child's interview being quoted verbatim in reports and publications related to this study.	
I agree for my child's GP to be notified of my participation within this study	
I give informed consent for my child to participate in the above study	

As stated in the information sheet, it may be that once the lead researcher has been through the interview they wish to interview your child again to clarify things noticed in the original interview. This is simply to ensure that they have a deeper understanding of their experience.

If a second interview is required and you wish for your child to take part, please initial the following box:

I DO content to my child/relative taking part in a second interview if required	
--	--

I wish to see a copy of the results and I would like it emailed/posted to:

.....
.....



Signature of Parent(s)/Guardian(s)

Name

Signature

Name

Signature

Name of researcher

Signature of researcher.....

Date: / / /

Appendix P

Participant assent form 16 and under

Assent Form



(Participants Under16)

Title of Project: *Young peoples' lived experiences of cancer: An Interpretative Phenomenological Analysis*

Name of Participant:

Name of Investigator: Joshua Spooner

	Please Initial:
I confirm that I have read the information sheet dated (version.....) for the above study	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected	
I understand that relevant sections of my medical notes and data collected during the study, may be looked at by the research team or staff within the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	

I understand that the information that I provide during this study will be processed and analysed as is required and in accordance with the Data Protection Act. This includes an audio recording of the interview. I understand that this information will be anonymised, all indefinable information removed and digital recordings will be destroyed after they have been transcribed. After completing the project, anonymised transcripts will be held at the university and then destroyed in line with university policy	
I agree to anonymised quotes from my interview being quoted verbatim in reports and publications related to this study.	
I agree for my GP to be notified of my participation within this study	
I agree to participate in the above study.	

As stated in the information sheet, it may be that once the lead researcher has been through the interview they wish to interview you again to clarify things noticed in the original interview. This is simply to ensure that they have a deeper understanding of your experience.

If a second interview is required and you wish to take part, please initial the following box:

I DO wish to take part in a second interview if required	
---	--

I wish to see a copy of the results and I would like it emailed/posted to:

.....

Signature of Participant

Name

Date:

Signature of researcher

Appendix Q

Participant debrief document



Debrief Sheet

Young peoples' lived experiences of cancer: An Interpretative Phenomenological Analysis

Thank you for taking the time to participate in this research. The purpose of this project was to gain a detailed insight into what it is like to be diagnosed with cancer as a teenager or young adult. Your contributions may now go on to help other young people who find themselves in a similar position.

I hope you found taking part interesting and enjoyable. However, if this experience has brought up any difficult thoughts or feelings, and you feel you would like to access some support, now, or in the future, we would recommend you speak to your parent/legal guardian or clinical care team. Additionally, please see the below list of organisations that can offer advice and support if required.

✦ **CLIC Sargent - Cancer charity for children and young people** Tel - 03003300803

Website <http://www.clicsargent.org.uk/content/cancer-information-youngpeople>

Community Forum

https://community.clicsargent.org.uk/?_ga=1.68041362.2034325135.1486377645

✦ **Cancer Research UK**

Tel - 0808 800 40 40 (9am-5pm Monday to Friday)

✦ **Macmillan Support Line**

Tel - 0808 808 00 00 (9am-8pm Monday to Friday)



✦ **The Samaritans**
Tel - 116 123

✦ **ChildLine**
Tel - 0800 1111

✦ **Your clinical care team**

✦ **Your GP**

Many thanks for your participation

Questions

If you have any questions or concerns about the research, please contact:

Joshua Spooner: Lead Researcher and Trainee Clinical Psychologist.
E-mail: spoone10@uni.coventry.ac.uk. Tel. 024 7765 7806.

Dr Carolyn Gordon, or Jackie Knibbs: Research Supervisors E- mail:
carolyn.gordon@coventry.ac.uk/ j.knibbs@coventry.ac.uk Tel. 024 7765 7806.

If you wish to make a complaint please contact the Associate Pro
-Vice-Chancellor,
Olivier Sparagano on olivier.sparagano@coventry.ac.uk

Appendix R

Interpretative Phenomenological Analysis procedure

Table 2.4 IPA analysis procedure (Smith, Flowers & Larkin, 2009)

Stage One: Identifying themes in the first case	The transcripts will be read a number of times in order to become familiar with the content. Parts that appear significant or interesting will be annotated and this stage may include preliminary interpretations.
Stage Two: Emerging themes	Once the transcript has been read, I aim to return to the beginning and comment on emerging theme titles. This may involve more psychological terminology and move the response to 'a higher level of abstraction'.
Stage Three: Connecting themes	Connections between emerging themes are sought, here similar themes are clustered, with superordinate themes transpiring. This analysis is an iterative process with emphasis on returning to the text to validate the themes ensuring the participant's account matches what has emerged.
Stage Four: Coherence of data	A table is created in which clusters of themes (subordinate) are labelled under a superordinate theme. At this stage it is suggested to include an identifier of where the data was gathered from, to facilitate finding the original source (name, page, line number). At this stage other themes may be cut from the

Appendix S

Examples extracts from coded transcripts

Example from participant 2:

318 Time check 18 min 43 sec

319 Yeah, you're losing everything just because of one disease,

320 it's really strange I don't know how to explain it...and then

321 then you meet as well, you meet other people, it is your

322 first time in a hospital...well it was for me... then you meet

323 other girls and there all lying there and they all have the

324 bald heads, and by then I had shaved my head but I was not

325 ready to show it to the world...but you see them and they

326 had just moved on... maybe because they have probably

327 been there for a longer time... so they have moved on...

328 you see them walking around and you get scared... I don't

329 know it's like...you know it's like quarantine (laugh)

330 Yeah, I know what you mean

331 Yeah you feel like you have been put in quarantine and that

332 everyone...because you don't see all of them outside...you

333 don't see girls with bald heads everywhere...so you feel like

334 you're in your own world and your trapped in there...But

20

Repetition of you're - not I - creating distance?

Losing sense of self / losing everything because of cancer Cost of illness

Not ready to show the world / Not adjusted to her appearance.

- Comparing self to others. - When is it ok to move on? Right vs Wrong?

Get scared seeing other

Locked away

It's like you're in quarantine

- Strong word "Quarantine" - expressing a different place / world - Sense of being diseased? - What does it mean to have cancer? - Put in quarantine

- See what's what - creating distance

- Not exposed to dis in the outside world why don't we see - or do we not look?

Trapped in another world

- Sense of not wanting to be there - feeling "trapped" by the disease.

Trapped in your own World - Away from normality

A whole new world

Same Quarantine

Prison

Example from participant 4:

632 what if I didn't do that, what if I never done

633 that, yeah

634 Yeah, and again in some respects, I mean what

635 are your feelings, I mean it might be a silly

636 question, but you know, because this is

637 happened, have you got any feelings about

638 your experience about going through

639 this experience?

640 A bit of frustration and anger, because I

641 thought like, why me (pause) like there's

642 people out there (crying) ok I don't know if

643 you want to hear it on here, but do drugs, do

644 drugs every day, do things out of the ordinary,

645 why haven't they got it

646 So, would you say it's hard to, to understand?

647 Yeah, like people who take life for granted and

648 I'm in hear (crying... long pause)

39

"Karma"
"Reinforced"

what if
Repetition of "what if"
- Sense of frustration or "Karma"

Why me
Angry about having cancer
"Why me"
- why me
Other people do worse things and are ok
- other people deserve it more than me?
Why have other people not got cancer?
- Fairness of life?
What is fair?
Quick for answers?
- Natural Justice -
Others take life for granted and I am here.
- No one should take life for granted?

Fairness of life
"A natural injustice"

www.celestrac.co.uk
and 500

Photos of data analysis

Photo one:



Photo two:

